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**PERSPECTIVES OF PARENTS WHO HAVE A CHILD DIAGNOSED  
WITH AN AUTISM SPECTRUM DISORDER**

by

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A Dissertation

Submitted to the Graduate Faculty

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Doctor of Education

Grand Forks, North Dakota

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2009

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This dissertation, submitted by Lori Ann Kalash in partial fulfillment of the requirements for the Degree of Doctor of Education from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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This dissertation meets the standards for appearance, conforms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

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## ABSTRACT

The purpose of this phenomenological study was to understand the experiences and perceptions parents of a child with an autism spectrum disorder have had. The study addressed the following research question: What were the parents' experiences and perspectives with regard to their child's diagnosis and treatment options?

For this interview study, 12 parents of children diagnosed with an autism spectrum disorder were ultimately selected and interviewed. The audio recorded interviews were transcribed and then examined for "significant statement" sentences. Next, clusters of meaning were developed into themes. These "significant statements" and themes were then used to create the formulated meanings of the participants' experiences. These formulated meanings were shared with three experts in the field of autism spectrum disorders to combat researcher bias. Finally, the formulated meaning statements were compiled to write a composite description that captured the essence of the participants' experience.

Seven themes emerged from the data analysis: (a) Despite parents expressing the concern for their child's development, the diagnosis of an autism spectrum disorder was not confirmed until years and/or doctor visits later. (b) Upon learning of their child's diagnosis, there was lack of guidance from medical professionals. (c) There were limited daycare options for parents, resulting in one parent quitting his or her job. This, along with insurance difficulties, was a financial burden. (d) The parents were torn between

their child with autism and their other children, family members, and friends. (e) There was a concern for their child's future. (f) Parents expressed feelings of being judged by the public because their child may look "normal" but does not behave in that manner. (g) There was a belief that vaccinations may have played some role in causing their child's autism.

Raising a child with an autism spectrum disorder is a difficult endeavor. The barriers and hardships that parents encounter may be lessened if the medical community and education professionals work together to give these parents the guidance they need and desire.



## CHAPTER I

### INTRODUCTION

The purpose of this study was to understand the experiences and perceptions parents of a child with an autism spectrum disorder have had that may provide parents of a child newly diagnosed with an autism spectrum disorder a better experience. I was interested in this topic due to my work with children diagnosed with these disorders. As a result of my work in this field, I have developed relationships with many families and have learned about some of their struggles and frustrations. Through the interview process, I gained a more thorough understanding of their experiences and hope to accurately convey these experiences to professionals in the field of autism to increase their empathy, understanding, and knowledge.

#### Autism Spectrum Disorders Overview

Autism spectrum disorders are characterized as pervasive developmental disorders that may result in impairments in cognitive functioning, social interaction, imaginative play, language development, and receptive and/or expressive communication (American Psychiatric Association, 2000).

Today, 1 in 150 individuals is diagnosed with autism, making it more common than pediatric cancer, diabetes, and AIDS combined. It occurs in all racial, ethnic, and social groups and is four times more likely to strike boys than girls. (Autism Speaks Inc., n.d.a, ¶ 1)

According to the research, there are many reasons for this rapid increase in the prevalence of autism spectrum disorders. Some of these reasons are directly related to

the diagnostic criteria. The current diagnostic criteria described in the DSM-IV-TR for autism spectrum disorders have been expanded to include individuals with co-morbid conditions. For example, a child can now be diagnosed as having an autism spectrum disorder and Attention Deficit Disorder or depression. Along with the expansion of the DSM-IV-TR criteria, the awareness and knowledge of healthcare and educational providers have increased. This increased knowledge and awareness have resulted in children being accurately diagnosed more often with autism spectrum disorders rather than being misdiagnosed with another disability (Aspy & Grossman, 2008).

Even though part of this increase in the diagnosis of autism spectrum disorders may be a direct result of the expansion of the DSM-IV-TR and the increased knowledge of professionals, some experts and parents also argue that the increase in these disorders is the direct result of external causes such as mercury poisoning, vaccination preservatives, and the increase and timing of vaccinations (Aspy & Grossman, 2008). On the other hand, there are professionals who argue that autism spectrum disorders are genetic and heritable (Attwood, 1998; Frith, 2000).

Autism spectrum disorders include a group of five disorders that is characterized as having impairments of varying degrees in communication skills, social abilities, and repetitive behaviors. The five disorders included on the autism spectrum include Autism, Asperger's Syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, and Rett Syndrome.

### *Autism*

Autism is a complex neurological disorder that impairs a person's ability to relate and communicate effectively with others, including reading people's emotions, holding



eye contact, and expressing his or her emotions. People with autism often exhibit rigidity for routines and engage in repetitive behaviors. According to the American Psychiatric Association (2000), people with autism have qualitative impairments in social interaction, communication, and display restricted repetitive and stereotyped patterns of behavior. In addition, delays in one of these three areas are manifested prior to the age of three years.

### *Asperger's Syndrome*

Asperger's Syndrome is a neurological disorder marked by difficulties in communication and social interaction. It is similar to classic autism in that people with Asperger's Syndrome have difficulty identifying and expressing their emotions, connecting with other people, holding eye contact, and reading people's faces and gestures. However, there are not delays in language or cognitive skills (Autism Speaks Inc., n.d.b, ¶ 2).

### *Childhood Disintegrative Disorder*

Childhood Disintegrative Disorder (CDD) is a neurological condition in which children develop normally for at least the first two years of life, then demonstrate a severe loss of social, language, play, motor, self-help, and communicative skills. Children with CDD have qualitative impairments in social interaction, communication, and display restricted repetitive and stereotyped patterns of behaviors, much like those diagnosed with classic autism. However, the loss of skills in children with CDD is much more dramatic and prevalent than in classic autism (American Psychiatric Association, 2000).

### *Pervasive Developmental Disorder-Not Otherwise Specified*

Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) is a neurological disorder on the autism spectrum that includes several of the symptoms and



characteristics of classic autism, but not all of the criteria. PDD-NOS may be described as “atypical autism.” People diagnosed with PDD-NOS do not meet the criteria for classic autism because of late age at onset, atypical symptomatology, or subthreshold symptomatology, or a combination of all of these. People diagnosed with PDD-NOS will display some of the same behaviors of those diagnosed with classic autism, including difficulty socializing with others, repetitive behaviors, difficulty holding eye contact, heightened sensitivities to stimuli, and difficulty transitioning (American Psychiatric Association, 2000; Autism Speaks Inc., n.d.c, ¶ 1-2).

### *Rett Syndrome*

Rett Syndrome is a developmental disorder most commonly found in girls. It is caused by mutations on the X chromosome on a gene called *MECP2* and can be diagnosed with a blood test. Rett Syndrome symptoms, which may be fatal, appear after an early period of apparently normal or near normal development followed by a stagnation of skills. This is followed by a period of regression where the child loses communication skills and purposeful use of her hands. Stereotyped hand movements such as handwashing, gait disturbances, loss of social engagement, and slowing of the normal rate of head growth become apparent. Other problems may include seizures and disorganized breathing patterns (International Rett Syndrome Foundation, 2008, ¶ 1-7).

### *Purpose of the Study*

Having a child with a disability presents unique experiences. By understanding the experiences these parents have had in regard to their children’s diagnosis, successful and unsuccessful interventions, worries and frustrations, and other insights they may

provide, the experience for parents of newly diagnosed children with an autism spectrum disorder might be improved.

### Research Question

With the increase in the incidence rate of autism spectrum disorders, it is important for medical professionals, educators, and parents of the newly diagnosed child to understand perspectives of parents who have already trudged this journey. This increase in understanding may have a positive impact on the relationship between parents and the professionals they encounter. The research question is: What were the parents' experiences and perspectives with regard to their child's diagnosis and treatment options?

### Delimitations of the Study

The following delimitations were identified in this study:

1. Participants in the study were parents of children diagnosed with an autism spectrum disorder, including Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), or Asperger's Syndrome.
2. Participants were selected from four different geographical locations within a pre-designated state in the Midwest.

### Conceptual Framework

When a child is diagnosed with a disability, the parents may experience many emotions. Many of these emotions may be the result of the parents losing the "normal" child they dreamed of and being left with the unknown. This process can be related to John Rolland's theory of chronic illness and Elizabeth Kubler-Ross's theory of coping with death.

Rolland (1994) has described the family life cycle in relation to chronic illness. His theory includes three phases: the crisis phase, the chronic phase, and the terminal phase. These occur throughout a chronic illness beginning with initial signs and symptoms and ending in death. The crisis phase begins with the initial signs of the disease and ends with an actual diagnosis. The chronic phase involves a period of adjustment leading the family to find a new “normal” way of living while dealing with abnormal conditions. The terminal phase is the final stage which ultimately begins with the death of the person diagnosed with the illness, followed by grief and mourning among family members.

The crisis phase and chronic phase described by Rolland can be aligned with the stresses experienced by families having a child diagnosed with a disability. For example, the crisis phase is the systematic time before the diagnosis. At this time, the family is realizing that something is unique about their child; each developmental milestone possibly becomes a state of crisis for the family. Next, the chronic phase is described as the day-to-day living of the family. After the diagnosis, the family needs to adjust and decide on treatment plans. In the chronic phase, the family has learned how to cope psychologically and organizationally while striving for their new “normal” way of living. Despite this, the crisis phase may continue to reoccur.

Kubler-Ross (1969) also described the process of grief a family member may travel through when coping with the death of a loved one. This, much like Rolland’s theory of the chronic and crisis phases, can be extended to include families coping with the disability of a family member. According to Bowe (2004), parents may be faced with shock and denial upon learning of the diagnosis. This may be followed by anger and



bargaining with God. During the bargaining stage, the parents may think, “If you cure my child, I promise to . . .” (Bowe, 2004, p. 11). Next, the parents may fall into a state of depression. It is hoped that this period is followed by acceptance of the disability.

Rolland’s (1994) theory of chronic illness and Kubler-Ross’s (1969) theory related to death guided the development of interview questions for parents of children with an autism spectrum disorder (Appendix B). For example, question two: Looking back, please reflect on when your child first displayed signs of having an autism spectrum disorder, and question three: Describe the process of how your child became diagnosed with an autism spectrum disorder, were aligned with the crisis phase described by Rolland. This crisis phase begins with the first sign of the disease and ends with diagnosis. These questions were also generated to relate to Kubler-Ross’s theory of coping with death of a loved one, specifically the first two phases: initial shock and possible denial of the diagnosis. Another example of how the interview questions were guided based on these theories involves question five: Reflect on the effective and ineffective interventions that have been utilized with your child. This is related to Rolland’s theory, precisely the chronic phase when the family needs to decide on treatment plans.

### Organization of the Study

In the first chapter, background information regarding autism spectrum disorders, as well as the purpose and significance of the study, were introduced. In addition, the research question and delimitations described the direction of the study. Finally, the conceptual framework that provided a direction for participant interview questions was identified. Chapter II includes a review of the literature, while the research methodology

utilized in conducting the study is described in Chapter III. In Chapter IV, the findings of the study are discussed. Last, a summary of the study, conclusions, and recommendations for future research are presented in Chapter V.

## CHAPTER II

### LITERATURE REVIEW

The experiences, either positive or negative, of parents who have a child diagnosed with an autism spectrum disorder may be directly related to many factors. The following review of the literature presents an in-depth description of the characteristics, possible causes, assessment tools, interventions, and early indicators of autism spectrum disorders, along with the stress associated with raising a child with disabilities.

#### Characteristics of Autism Spectrum Disorders

Not every person will exhibit all of the characteristics associated with autism spectrum disorders or display them to the same degree due to the fact that autism spectrum disorders are heterogeneous. This simply means that each individual with autism spectrum disorders is unique. Despite this, there are common characteristics that are associated with autism spectrum disorders, including communication difficulties, impairments in social interaction, and restricted repetitive behaviors (Aspy & Grossman, 2008). The following section includes a detailed description of these characteristics.

#### *Communication Impairments*

Communication difficulties limit the ability of people with autism spectrum disorders to interact appropriately with others. These common characteristics include the following: repeating words or phrases, displaying echolalia (the uncontrollable repetition



of words spoken by another), and literally interpreting words or phrases used figuratively. People with autism spectrum disorders also have difficulty with rules of conversations, responding to social greetings, reading non-verbal communication, and expressing their thoughts and feelings. Other difficult tasks for these individuals include following directions, understanding language with multiple meanings, and talking about others' interests (Aspy & Grossman, 2008).

### *Social Impairments*

Another area of concern for these individuals is social impairments. These impairments make it difficult for appropriate social interaction and the making of friends. These individuals may have difficulty recognizing the thoughts and feeling of others, using proper eye contact in conversation, and maintaining their own personal space. They may be easily bullied by others and can be taken advantage of quite easily. They may also have trouble joining activities, understanding jokes, and making and keeping friends (Aspy & Grossman, 2008).

### *Restricted Repetitive Behaviors*

Repetitive behaviors may look different for individuals on various positions on the autism spectrum. For example, people with Asperger's Syndrome tend to be preoccupied with specific interests. They have a vast amount of knowledge regarding this interest and may be able to recite countless details. These intense interests overtake conversations with others. In contrast, individuals with other autism spectrum disorders tend to engage in repetitive motor movements such as "clapping, finger flicking, rocking, or fascination with movements or parts of objects" (Aspy & Grossman, 2008, p. 14). Transitioning from one activity to another is an area of difficulty for these individuals, as



well. There may be a strong necessity for sameness and a preference for predictable events, as well as difficulty with stopping a task before they have completed it (Aspy & Grossman, 2008).

### Etiology

Currently, the exact cause of autism is unknown. The explanations for the cause of autism spectrum disorders vary. Due to the importance of early intervention for people with autism spectrum disorders, many researchers are focusing on finding the specific genetic differences in people with autism spectrum disorders in the hopes that these may become future early indicators (National Institute of Child Health and Human Development, 2005). Other areas of focus include brain development and head circumference in individuals with autism spectrum disorders (Berman, 2001; Boeree, 2009; Courchesne, 2004; Hashimoto et al., 1995; Mills Schumann et al., 2004; Sparks et al., 2002; Taylor, Smiley, & Richards, 2009). By identifying the specific genes and areas of the brain that are affected in individuals with autism spectrum disorders, genetic tests may be used to identify autism spectrum disorders at an earlier age, resulting in earlier intervention than might happen without these tests (National Institute of Child Health and Human Development, 2005).

### *Genetic Impairments in Individuals With Autism Spectrum Disorders*

There are many differences in the genetic makeup and in the development of various regions in the brain of individuals with autism spectrum disorders. For instance, according to the National Institute of Child Health and Human Development (2005), there are currently up to 12 genes that may be affected in people with autism. The

affected genes in each individual with autism spectrum disorders vary from person to person. This may account for the spectrum of disorders and the severity of these disorders from individual to individual. The genes that are affected may impact different areas of the brain, thus explaining the complexity of the disorder and how each individual is so different from the next.

The National Institute of Child Health and Human Development (2005) indicated that the genes that are most likely to show impairments are chromosomes 2, 7, 13, 15, 16, 17, and the X chromosome. Each of these chromosomes is responsible for specific development in the brain. These are described below:

Chromosome 2 is responsible for the growth and development related to the brain stem and the cerebellum. This is home to the Homeobox, which is responsible for controlling growth and development.

Chromosome 7 is related to speech and language development, which affects people with autism spectrum disorders.

Chromosome 13 has as many as 600 to 700 genes associated with this chromosome. Researchers have found a link between chromosome 13 and autism, along with a variety of other genetic disorders.

Chromosome 15 showed impairments in 4% of the individuals tested. Chromosome 15 is also associated with Prader-Willi Syndrome and Angelman Syndrome that include characteristics of a puppet-like jerky gait, hand flapping, and the tendency to smile and laugh almost continuously. People with these syndromes also have speech impairments, with verbal expressive language more severely affected than receptive or

non-verbal communication. These syndromes are behaviorally similar to autism spectrum disorders.

Chromosome 16 impairments are responsible for Tuberous Sclerosis. Tuberous Sclerosis includes seizures and many autism-like symptoms.

Chromosome 17 is associated with galactosemia, which causes developmental delays if left untreated. This gene is also responsible for the transportation of serotonin.

The X chromosome causes Fragile X Syndrome and Rett Syndrome by impairments of this chromosome. Rett Syndrome is a syndrome on the autism spectrum. Fragile X Syndrome contains many similarities to autism spectrum disorders.

Impairments to the X chromosome may explain the higher incidence rate of autism disorders in boys compared to girls. Females have an XX genetic makeup and males have an XY genetic makeup. If autism spectrum disorders are caused by impairments to the X chromosome, females have an extra X chromosome to rely on if one of the X chromosomes is affected or impaired. Thus, the impairments may be masked, unless both chromosomes are affected. Males, on the other hand, with an XY genetic makeup, do not have the extra X chromosome to rely on.

#### *Brain Abnormalities in Individuals With Autism Spectrum Disorders*

In addition to these chromosomal impairments, there are additional areas of the brain that are affected in people with autism spectrum disorders. The brain is organized in such a way that dysfunction at one level of organization, or damage to a particular area of the brain, is responsible for a fairly specific behavior abnormality, such as the inability to have “normal” social and communication skills (Berman, 2001, ¶ 12).



Research indicates that many cases of autism spectrum disorders show characteristics of accelerated brain growth and size when these children are between the ages of birth and four years, followed by a slowed rate of growth (Sparks et al., 2002). Courchesne (2004) discusses that the head circumference of a child with ASD shows a small size at birth, progressing to an above average size between the ages of 6 and 14 months, and then continues to show a fast rate of growth until two years of age. The accelerated brain growth in children may be a warning indicator of autism spectrum disorders to the medical professionals during well baby visits, thus helping medical professionals diagnose autism at an earlier age.

In addition to the brain growth differences in individuals with autism spectrum disorders, there also appears to be a decreased amount of blood flow to the left hemisphere of the brain. The left hemisphere is responsible for language functioning. The decreased amount of blood flow to the left hemisphere may result in language impairments in individuals with autism spectrum disorders (Taylor et al., 2009).

Additional brain abnormalities in people with autism spectrum disorders are described below:

**Amygdala:** The amygdala is responsible for emotions such as fear. During the ages of 7 ½ to 12 ½ years, the amygdala is larger in people with autism spectrum disorders than in typically developing peers of the same age. Then, during the ages of 12 ¾ to 18 ½ years, there is not a significant difference in the size. It appears that the amygdala is growing too big, too fast, thus causing impairments in this area (Boeree, 2009; Mills Schumann et al., 2004).

**Hippocampus:** The hippocampus is responsible for memories. The hippocampus is larger in individuals with autism spectrum disorders at all ages when compared to their typically developing same-age peers (Boeree, 2009; Mills Schumann et al., 2004).

**Cerebellum:** The cerebellum is responsible for movements and possibly speech, learning, emotions, and attention. The cerebellum, specifically lobes VI and VII, has been shown to be hypoplastic or smaller sized, in people with autism spectrum disorders. The smaller these lobes, the more severe the autism spectrum disorders. In addition to the size difference, there are a reduced number of perkinge cells in the cerebellum in people with autism spectrum disorders. The perkinge cells are rich in serotonin. Serotonin is responsible for regulating moods, arousal, and inhibition (Boeree, 2009; Hashimoto et al., 1995).

### *Vaccinations*

A controversial theory of the cause of autism spectrum disorders is vaccinations. One such vaccination is the MMR (measles, mumps, rubella) vaccination. Wakefield et al. (1998) conducted a study involving the MMR vaccination and reported that the measles virus contained in the MMR vaccination was responsible for causing autism. They stated that toxins were allowed to leak into the brain due to bowel inflammation following the vaccination, which, in turn, was causing autism spectrum disorders (Taylor et al., 2009; Wakefield et al., 1998). According to Taylor et al. (2009), shortly after reporting this claim the researchers conducting the study received criticism by many and Wakefield and his partners recanted their findings. Since Wakefield et al.'s (1998) claim, several studies have been conducted involving the MMR vaccination. To date, a link showing a cause and effect relationship between the MMR vaccination and autism



spectrum disorders has not been found. For example, Baird et al. (2008) found no association between the measles vaccination and autism spectrum disorders. In addition, Smeeth et al. (2004) conducted a study with over 5,000 participants. Approximately 1,200 of these participants were diagnosed with a pervasive developmental disorder and approximately 4,400 were not. Smeeth et al. reported that the “MMR vaccination is not associated with an increased risk of pervasive developmental disorders” (p. 963). Furthermore, Makela, Nuorti, and Peltola (2002) conducted a study of over 535,000 children who were vaccinated in Finland. Of these participants, 352 were diagnosed with autism. However, none of the children with autism made hospital visits for inflammatory bowel diseases. These bowel diseases, according to Wakefield et al., were responsible for the release of toxins in the brain causing autism spectrum disorders. Therefore, Makela et al. concluded that there is no association between the MMR vaccination and autism.

Vaccinations containing thimerosal have also been hypothesized as a possible cause of autism spectrum disorders. Thimerosal is a preservative that contains mercury. Since this claim has been made, efforts have been made to exclude thimerosal from childhood vaccinations within the United States. With this reduction in exposure to thimerosal, one would expect the prevalence of autism spectrum disorders to decrease. However, throughout the study period from 1995 to 2007, the prevalence of autism continued to increase. The research suggests that exposure to thimerosal during childhood is not a primary cause of autism (Schechter & Grether, 2008). Another study compared the prevalence of autism with exposure to thimerosal in California, Sweden, and Denmark (Stehr-Green, Tull, Stellfeld, Mortenson, & Simpson, 2003). In all three

locations, the prevalence of autism spectrum disorders continued to rise and accelerate in the early 1990s, despite the vaccinations in Sweden and Denmark decreasing in the amount of thimerosal they contained as well as the elimination of the use of thimerosal in all vaccines by the early 1990s.

### *Birth Complications*

Another theory for the cause of autism spectrum disorders is birth complications, specifically those occurring prenatally and perinatally. Brimacombe, Ming, and Lamendola (2007) studied prenatal and birth history with relation to the onset of autism. They found that a history of “vaginal bleeding, prolonged labor and prematurity” (p. 73) was higher among those diagnosed with autism when compared nationally and in the state of New Jersey. Brimacombe et al. reported that problems within the prenatal stage of development might be associated with an increased risk for autism. Johansson et al. (2002) also found that uterine bleeding during pregnancy may be a cause of autism spectrum disorders. Furthermore, Hultman, Sparen, and Cnattingius (2002) found that neonatal factors that impacted fetal growth, such as “daily smoking . . . , maternal birth outside [of] Europe and North America . . . , cesarean delivery . . . , being small for gestational age . . . , a 5-minute Apgar score below 7 . . . , and congenital malformations” (p. 417), along with intrauterine factors, are associated with an increased risk of autism. However, Brimacombe et al. suggested that the cause of cesarean delivery is a factor, as well. They stated that “while repeat cesarean should have little impact on pregnancy, emergency cesarean may produce great stress on both the mother and child” (pp. 77-78), thus becoming a risk factor for autism spectrum disorders. In contrast, a study conducted by Glasson et al. (2004) suggested that cases of classic autism had more birth



complications than those with Pervasive Developmental Disorder-Not Otherwise Specified and Asperger's Syndrome. Moreover, they concluded that autism is likely to be caused by multiple obstetric factors, rather than a single obstetric factor. However, Glasson et al. argued "the increased prevalence of obstetric complications among autism cases is most likely due to the underlying genetic factors or an interaction of these factors within the environment" (p. 618). Birth complications such as oxygen deprivation, viral infections, and metabolic imbalances have been associated with an increased risk of autism spectrum disorders (Taylor et al., 2009).

#### Autism Spectrum Disorder Assessment Tools

Intensive early intervention services are the key to success for children diagnosed with an autism spectrum disorder (Autism Speaks Inc., n.d.d, ¶ 4). Proper identification at an early age is a necessity, because children with autism spectrum disorders will need further interventions and programming designed to meet their specific needs. Currently, there are a number of autism checklists and screening tools utilized by professionals for identifying autism spectrum disorders. This section includes a summary and review of several valid autism assessment tools.

#### *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV-TR*

The *Diagnostic and Statistical Manual of Mental Disorders: DSM-IV-TR* is the most widely accepted diagnostic tool in the United States for diagnosing autism spectrum disorders. The manual has changed significantly since autism was identified over 50 years ago. The current diagnostic criteria described in the DSM-IV-TR for autism spectrum disorders have been expanded to include individuals with co-morbid conditions.

In addition, the most current version, the DSM-IV-TR, separates autism spectrum disorders into five separate categories across a single spectrum. These include Autism, Pervasive Developmental Disorder-Not Otherwise Specified, Asperger's Syndrome, Rett Syndrome, and Childhood Disintegrative Disorder. The diagnostic criteria for disorders across the autism spectrum examine the individual's social, communication, and repetitive behaviors (New York State Department of Health, 1999).

### *Checklist for Autism in Toddlers*

The Checklist for Autism in Toddlers (CHAT) is a screening tool used to identify children at risk for being diagnosed with an autism spectrum disorder. Professionals administer it when the child is between the ages of 18 to 36 months. The parents complete the first nine items and the professional involved in the assessment completes the following five items based on his or her observations of the individual being screened. These behaviors examined by the CHAT include joint attention, including pointing to show and gaze monitoring, as well as pretend play (National Autistic Society, 2008, ¶ 4-5). If the results of the CHAT suggest that an individual has signs of autism spectrum disorders, an in-depth evaluation is the next step. The advantages of the CHAT include the ability to screen children as young as 18 months of age, the ease and brevity of administration, the lack of required training for administration of the assessment, and the effectiveness of identifying children who are at risk of having an autism spectrum disorder. Despite the advantages of administering the CHAT, it is important to remember that the CHAT cannot be used to make a formal diagnosis and that it may give false results and identify children incorrectly (New York State Department of Health, 1999).



### *Childhood Autism Rating Scale*

Staff of the Treatment and Education of Autistic and Related

Communication-handicapped Children (TEACCH) program developed the Childhood Autism Rating Scale (CARS) over a 15-year period using a database of over 1,500 autism cases. Since its development in 1980, a number of studies have been done on the accuracy of the CARS, with findings assessing it at percentage rates of accuracy as high as 98% in diagnosing children accurately with autism spectrum disorders (Secor, n.d., ¶ 2). The advantages of using the CARS include the consistency of the data collected, the structure it provides to the assessment process, the ability to be used with children as young as two years of age, the ability to measure the severity of autism symptoms, and the availability of materials. As with the CHAT, there are limitations of using the CARS. These include the giving of false results and identifying children incorrectly, along with the results being unreliable if administered by an untrained individual (New York State Department of Health, 1999).

### *Interventions*

At this time, there is not a cure for any of the disorders on the autism spectrum. Despite this, there are many interventions that have been developed and studied by professionals. These interventions focus on strengthening areas in which children with autism spectrum disorders have deficits.

### *Proven Effective Interventions*

Although there is not a single proven method to teach children with autism, there are practices which have been scientifically validated and considered to be effective in treating children with autism spectrum disorders in combination with matching the needs

of the children, their setting, and the family. These include direct instruction, TEACCH, applied behavior analysis, and social stories. Experts agree that an eclectic approach, which includes these interventions, is considered “best practice” for children with autism spectrum disorders (Taylor et al., 2009).

#### *Direct Instruction*

Direct instruction may be used to teach communication, social, and cognitive skills. It involves careful analysis of the tasks to be taught while incorporating questioning, modeling, and guided practice, followed by independent practice (Taylor et al., 2009).

#### *Treatment and Education of Autistic and Related Communication-handicapped Children (TEACCH)*

Eric Schopler developed the Treatment and Education of Autistic and Related Communication-handicapped Children (TEACCH) program in the early 1970s. The primary intent of the TEACCH program is to adapt the environment so it is highly structured and predictable to meet the needs of the child with autism. Adaptations may include reducing external stimuli, organizing the environment, developing visual schedules and work systems, making clear expectations, and utilizing visual stimuli to limit verbal instruction from adults. The goal of the TEACCH program is to foster independence in children with autism spectrum disorders (Taylor et al., 2009; TEACCH Autism Program, 2006, ¶ 1).

## *Applied Behavior Analysis*

Dr. O. Ivar Lovaas, a clinical psychologist, developed Applied Behavior Analysis (ABA), otherwise known as discrete trial training, in the 1970s. Discrete trials are utilized to teach the desired behaviors and are defined as:

a set of acts that contains a stimulus or antecedent, a behavior, and a consequence. One discrete trial is comprised of giving a cue, observing the student's response, and presenting a correction or reinforcer. . . . As the child's response becomes more reliable, the prompts are withdrawn until he or she responds independently. (Taylor et al., 2009, p. 381)

The goal of ABA is to change the individual to adjust to the environment, rather than changing the environment to adjust to the child, while utilizing behavioral observation, positive reinforcement, and prompting to teach the steps of a desired behavior. Some sort of reward follows the child's behavior when he or she performs each step correctly.

ABA is the most proven research based intervention shown to produce behavior changes in children with autism spectrum disorders.

## *Social Stories*

Social Stories were developed by Carol Gray in the 1990s to address the social needs of children with autism spectrum disorders. Social Stories are described as short stories about specific, commonly encountered situations that contain simple sentences and optional illustrations. The goal of Social Stories is to improve the understanding of social situations, to teach specific social skills, to introduce change in the environment, and to provide information about novel situations (Gray, 2000; Taylor et al., 2009).

## *Unsupported Interventions*

Many parents who have a child diagnosed with autism are willing to try anything that may help their child. However, there are many interventions available that have not



been scientifically validated. Some of these alternative treatments include facilitated communication, hormone therapies, auditory integration therapy, special diets, and many others. Although these interventions are showing promise in some individuals with autism spectrum disorders, they have yet to be validated (Taylor et al., 2009).

### Early Indicators of Autism Spectrum Disorders

Early intervention is a key indicator of success for children diagnosed with an autism spectrum disorder. Therefore, early identification is necessary. According to Beauchesne and Kelley (2004), parental concern regarding a child's development may be an effective screening tool and indicator for autism spectrum disorders. According to Glascoe (1997), parental concerns regarding their child's motor, language, global/cognitive, and performance in school were highly effective in identifying children with disabilities, specifically 79% of the 56 children later identified with a disability. In addition, Brereton, Tonge, MacKinnon, and Einfeld (2002) argue that an effective screening device for the diagnosis of autism spectrum disorders includes data collected from a well-developed parent report questionnaire.

To date, numerous studies have been conducted to identify other early signs of autism spectrum disorders, along with additional studies aimed at identifying signs that would lead to earlier identification. Baranek (1999) suggests that there are slight indicators of autism present as early as 9 to 12 months in the areas of sensory processing, sensory-motor functions, and social responses. In addition to these early indicators, the lack of pointing at objects of interest and impairments in gaze monitoring and pretend play, which are all items included on the CHAT, were pinpointed as early indicators of autism spectrum disorders (California Departments of Education and Developmental

Services, 1997). Moreover, Beauchesne and Kelley (2004) propose that, within the first year of development, children with pervasive developmental disorders display impairments in social interaction, lack a social smile, have hypotonia, display poor attention, and have unusual visual interests. Additionally, by the second year of development, these children tend to ignore people, have a preference to be alone, display an empty gaze, and have a lack of gestures and emotional expression. Furthermore, Landa and Garrett-Mayer (2006) suggest that there are variations in typical language development, along with language delays by 24 months of age.

#### Experiences of Parents Who Have a Child Diagnosed With an Autism Spectrum Disorder

Parents who have a child diagnosed with a disability are faced with many challenges. This portion of the literature review will examine some of the experiences and opinions of other parents who have a child diagnosed with an autism spectrum disorder. This information is provided as a supplement to the information gained from the parents I interviewed in hopes of better capturing their experiences.

#### *Parental Stress Associated With Caring for a Child With a Disability*

Many studies have been conducted regarding the amount and types of support provided to parents of children with disabilities and how these may impact stress levels. Rao and Beidel (2009) conducted a study of 15 parents of children with high functioning autism and 15 parents of typically developing children. They concluded the parents of children with autism experience more parenting stress than those of typically developing children. However, Johnston et al. (2003) argued that lower stress levels in parents of children with disabilities are associated with support from within the nuclear family. In



addition, support from one's spouse is critical for the acceptance of the child's disability (Renty & Roeyers, 2005). Furthermore, lower levels of stress are associated with parents of children with disabilities who have the support of their extended family. These lower levels of stress exist even if the extended family, from which there is support, resides in far-distant locations (Hastings, Thomas, & Delwiche, 2002; Renty & Roeyers, 2005; Trute, 2003). In addition, the support from friends and members of the community is helpful to parents of children with disabilities, thus lowering their stress levels (Trivette & Dunst, 1992). These types of support systems assist the parents in coping with the strain of raising a child with special needs (Renty & Roeyers, 2005).

#### *Parental Experiences With Treatment Options*

Green (2007) interviewed 19 parents about their experiences with treatments for their child diagnosed with autism. Of the 19 interviewed, Green ultimately included the perspectives of 18 of the parents who had experience with the treatments discussed in the study. There are two reasons parents choose specific treatment options for their child with autism. These include relying on the testimonials from other parents and the information they found while researching on the Internet. Green argued, "It is perhaps not surprising that treatments that lack evidence continue to be used. A positive parental report may have a ripple effect as it is passed on to parents of children who have been recently diagnosed" (p. 100). Moreover, the source of the information tends to have an impact on the duration and the perceived outcomes of using the treatments. For example, "for parents who receive their information from other parents, there may be a hope that 'if it worked for their child then it must work for mine'" (p. 100).

### *Parental Experiences With the Diagnostic Process*

Renty and Roeyers (2005) conducted a survey study regarding experiences with the diagnostic process, education for the child, and support consisting of 244 parents who had a child with an autism spectrum disorder. Of these 244 parents, 15 participated in supplemental interviews. The major assertion from the study revealed that parents experienced difficulties throughout the diagnostic process, with the education provided for their child, as well as the accessibility of service provisions for their child. Schall (2000) argued that the parents interviewed in her study “discussed an overwhelming number of visits to doctors, psychologists, hospitals and therapists to try to understand their child’s problems” (p. 412). In addition, the parents reported that the medical professionals disregarded their experiences and opinions regarding their child. Moreover, Goin-Kochel, Mackintosh, and Myers (2006) reported that parents of children with autism spectrum disorders who brought their concerns to the physicians had difficulties obtaining an actual diagnosis. Heidgerken, Geffken, Modi, and Frakey (2005) described the path to diagnosis and treatment of the disorders as a difficult process that required parents to encounter many professionals before receiving an actual diagnosis. This leads to the diagnosis being prolonged, thus resulting in lost intervention time for these children.

In addition to diagnostic difficulties, a study conducted by Nesbitt (2000) concluded that parents of children with autism feel there is a lack of information available to them regarding appropriate educational opportunities, social services, leisure services, and health service, along with how to access these services. Whitaker (2002) supported these findings in a study of preschool support for children with autism. He stated that



there is a need for additional information regarding local educational and support options for parents of children with autism. Parents of children with autism expressed concerns of being overwhelmed with finding reliable and relevant information given the vast amount of information available via the Internet (Nesbitt, 2000; Whitaker, 2002). Furthermore, one major theme that emerged from an interview study conducted by McCabe (2008) was parents feeling confused and desperate due to the lack of information provided after the diagnosis of the autism spectrum disorder.

*Early Indicators of Autism Spectrum Disorders  
as Viewed by Parents*

Parent interview studies have been conducted concluding that autism presents itself at an early age, leading parents to question their child's development between the ages of 12 and 24 months. Schall (2000) reported that two out of the three middle class families interviewed for her study shared that their children were developing normally until about 18 months of age. The third family described a loss of normal development in their child at the age of 24 months. In addition, Goin and Myers (2004) examined home videos of 12 typically developing children and of 12 children diagnosed with infantile autism. They described five identifiable behaviors that were noticeably different between these two groups of children. These behaviors included poor social interaction, the lack of a social smile, no appropriate facial expressions, hypotonia, and being easily distracted. Additional differences continued to present themselves between the ages of 12 to 24 months. For example, the children with autism tended to ignore others around them, preferred to play alone, had a lack of eye contact and appropriate gestures or expressive postures, were very calm, displayed unusual postures and hypoactivity, and

lacked the expression of emotions. Furthermore, Baird, Cass, and Slonims (2003) identified the following characteristics as present by 12 months of age: lack of social smile and appropriate facial expression, poor attention, impaired social interaction, ignoring people, a preference for aloneness, a lack of eye contact, a lack of appropriate gestures and emotional expression, less looking at others, less pointing, and less showing of objects. Additionally, they concluded that many parents are expressing concerns about their child's development at about 18 months of age.

### Summary

Autism spectrum disorders are pervasive developmental disorders that are characterized by difficulties in the three areas of development. This triad of impairments includes difficulties in social communication, social relationships, and imaginative thought. At this point in time, the exact cause of autism is unknown. The explanations for the cause of autism spectrum disorders vary. However, many studies have been conducted examining the cause. These include studies involving genetic components and environmental factors involving birth complications and vaccinations. Due to the importance of early intervention for people with autism spectrum disorders, many researchers are focusing on identifying the early indicators of autism to diagnose autism spectrum disorders as early as possible. There are slight indicators of autism present as early as 9 to 12 months in the areas of sensory processing, sensory-motor functions, and social responses. In addition, the lack of pointing at objects of interest, impairments in gaze monitoring, and difficulties with pretend play are also early indicators for autism.

There are a variety of assessment tools utilized for the screening and diagnosis of autism spectrum disorders. Currently, the *Diagnostic and Statistical Manual of Mental*



*Disorders:* *DSM-IV-TR* is the most widely used diagnostic instrument for autism spectrum disorders. However, the Checklist for Autism in Toddlers (CHAT) and the Childhood Autism Rating Scale (CARS) have been identified as useful screening tools based on their ease of use and reliability.

At this time, there is not a cure for any of the disorders on the autism spectrum. Despite this, there are many interventions that have been developed and studied by professionals. These interventions focus on strengthening the deficits of children with autism spectrum disorders.

Although there is not a single proven method to teach children with autism, there are practices which have been scientifically validated and considered to be effective in treating children with autism spectrum disorders in combination with matching the needs of the child, his or her setting, and the family. Experts suggest that designing a program utilizing an eclectic approach might include direct instruction, Treatment and Education of Autistic and Related Communication-handicapped Children (TEACCH), Applied Behavior Analysis (ABA), and Social Stories.

Lastly, parents of children with disabilities have a great deal of stress in their lives. Not only do they have to care for a child with a disability, they are overwhelmed by the amount and reliability of information available to them via the Internet. They also receive little guidance from the professionals upon learning of their child's disability. Having a strong support system from both nuclear and extended families, as well as friends and neighbors, may lessen this stress.



### CHAPTER III

#### METHODOLOGY

The purpose of this study was to understand the experiences and perceptions parents of a child with an autism spectrum disorder have had that may provide parents of a child newly diagnosed with an autism spectrum disorder a better experience. Utilizing the framework for a phenomenological study, as outlined by Creswell (2007), the study addresses the following research question: What were the parents' experiences and perspectives with regard to their child's diagnosis and treatment options? Throughout Chapter III, the following are presented: research design, participant selection, data collection methods, trustworthiness, measures for data analysis, and the introduction of significant themes.

#### Phenomenological Research

"A *phenomenological study* describes the meaning for several individuals of their *lived experiences* of a concept or a phenomenon" (Creswell, 2007, p. 57). This approach is appropriate when the researcher is trying to describe what all participants in the study have in common within a certain phenomenon (Creswell, 2007).

#### Moustakas's Phenomenological Research Methods

Moustakas's procedures, as outlined by Creswell (2007), were utilized to guide this study. These include determining the importance of understanding the common experience and if it is of interest to study, investigating the lived experience, collecting

data using in-depth interviews with individuals who have experienced the data, and asking open-ended questions with regard to the phenomenon. The researcher then analyzes the data by highlighting significant statements regarding the participants' experience of the phenomenon (horizontalization); developing clusters of meanings; writing a description of the participants' experience (textural description); writing a description of the setting which influenced how the phenomenon was experienced by the participants (structural description); and by using the textual and structural descriptions, writing a description that captures the essence of the phenomenon (essential, invariant structure). To capture the essence of the phenomenon in this study, member checking, peer examination, saturation of data, and rich, thick descriptive writing were used (Glesne, 2006).

#### Participant Selection

Only parents who have a child diagnosed with an autism spectrum disorder were asked to participate in this study. Letters of invitation were sent to the presidents of three various support groups for parents of children with autism spectrum disorders, special education case managers for children with autism spectrum disorders, and directly to parents of children with autism spectrum disorders. In addition, contacts were made by attending parent support group meetings for parents who have a child diagnosed with an autism spectrum disorder. At the meetings, the study was described and a voluntary sign-up sheet was made available. This allowed interested parents to be contacted. The "snowball effect" was also relied upon by asking those previously interviewed to recommend other parents who may be interested in sharing their stories. Gathering of

participants continued until saturation of data was reached. This resulted in interviews with 12 participants from four separate geographical locations within a midwestern state.

#### Protection of Human Rights

To conduct this study, the Institutional Review Board at the University of North Dakota reviewed the research protocol. Throughout the study, protection of privacy and of human subjects was assured. This was accomplished by informing participants of the purpose of the study, giving permission to the participants to withdraw at any time, asking the participants to give written consent (Appendix A), using pseudonyms during the interview transcription process, altering identifying information, and locking recorded interviews in a file cabinet separate from the list of interviews.

#### Description of the Setting

The setting for this study was a rural midwestern state. Interviews were conducted in four separate geographical locations within this state.

#### Materials

Open-ended parent interview questions (Appendix B), a site observation form (Appendix C), an interview transcription form (Appendix D), and a formulated meaning form (Appendix E) were utilized during this study. These materials were chosen as a means to conduct the interviews and to subsequently analyze the data.

An open-ended parent interview was used to collect the data for this study. The interview began with asking the parents to converse about their diagnosed child. As the interview progressed, they were asked to reflect on when they first questioned their child's development, the diagnostic process, the interventions they utilized with their child, their experiences with healthcare professionals, support systems they have in place,



and advice they would give to a family with a newly diagnosed child. They were also asked to examine 14 word cards (success, anxious/worried, touched/moved, angry, guilt, important to me, torn between, sad, trust/rapport, strong conviction or belief, happy, lost, frustrated, and surprised) and comment on the cards that had specific meaning to them. The purpose of the word cards was to assist the parents in engaging in deeper examination and reflection of their experience as a parent of a child diagnosed with an autism spectrum disorder.

The site observation form was utilized to write observation field notes. The interview transcription form was used for transcription of all conducted interviews. Lastly, a formulated meaning form was developed to organize the meaningful statements of the interviewees and used as a means to guide the member checking and peer examination processes.

### Procedures

#### *Observations*

Observing while taking detailed field notes is one component of qualitative research methods. Throughout the observation portion of this study, I was a participant observer in a support group for parents. The president of a support group for parents of children with autism spectrum disorders became the gatekeeper and negotiated access to the group. After gaining access, I attended four monthly meetings of a support group for parents who have a child diagnosed with an autism spectrum disorder. During site observations, I was an observer, but interacted with possible research participants throughout the observation process. The goal was to “make the strange familiar and the familiar strange” (Glesne, 2006, p. 51), while attempting to formulate generalizations

about this particular social situation. As I continued to attend the support group meetings, my role in this setting evolved. At the first meeting, I was introduced to the group by the support group president. He then gave me time to speak to the group about my interest in autism spectrum disorders, my experience working with children on the spectrum, my educational background, and ultimately the intentions of my study. As I continued to attend the monthly meetings, the parents seemed to become more and more comfortable with my presence as many interacted with me, both socially and for professional advice. Some topics of conversation included possible strategies for difficult behaviors their children were displaying, information on possible interventions, and useful resources for parents. By becoming a frequent visitor to a support group for parents of children with autism spectrum disorders, I was able to develop the rapport and relationships necessary to conduct a productive interview, as well as gain contacts of willing participants.

### *Interviewing Process*

For this study, only parents of children diagnosed with an autism spectrum disorder were interviewed. Participants were invited to participate in one to three recorded interviews with follow-up interviews scheduled when additional time or clarification of content was needed.

All interviews occurred in the parents' homes to assist with comfort and convenience to the participants. Each interview was approximately 90 to 120 minutes in length. Written permission was obtained at the time of the interview to audio record the interviews for transcription and analysis at a later time. The interview questions were used as a guide to help the interview stay on track, but these questions remained flexible

with new questions emerging based on the participants' responses and/or the need for the clarification and deeper insight into their experiences. During the interview, field notes were taken to record relevant information and other insights gained during the interview process.

The participant learning as an observer precedes the development of interview questions. What is seen and heard among the people of circumstance and interest becomes the basis for the construction of one's interview questions. There is a relationship between research and interview questions; however, "interview questions tend to be more contextual and specific than research questions" (Glesne, 2006, p. 81). In addition, their development "requires creativity and insight, rather than a mechanical translation of the research questions into an interview guide" (Maxwell, 1996, p. 74). Potential interview questions were formulated to gain insight into the phenomenon. These included:

1. Tell me about your child starting with the beginning.
2. Looking back, please reflect on when your child first displayed signs of having an autism spectrum disorder.
3. Describe the process of how your child became diagnosed with an autism spectrum disorder.
4. With regard to healthcare services (doctoring, dentist, optometrist, etc.), what have your experiences entailed?
5. Reflect on the effective and ineffective interventions that have been utilized with your child.



6. The interviewees were shown word cards (success, anxious/worried, touched/moved, angry, guilt, important to me, torn between, sad, trust/rapport, strong conviction or belief, happy, lost, frustrated, and surprised) and asked to reflect on what came to mind with regard to their child with autism spectrum disorders and any experiences they have had.
7. Describe the types of support systems that are in place for you.
8. What advice would you give to a parent who has a child recently diagnosed with an autism spectrum disorder?
9. Please take some time to tell me anything else you would like to share with me that you have not had the chance to do so already.

The purpose of the study was shared with the participants and the opening statement, "Tell me about your child starting with the beginning," allowed the parents to begin sharing their story while allowing the other questions to emerge. While listening to an interview, new questions were generated based on the participant's response, the need for further clarification, and the insight gained during the process. At the end of the interviews, the participants were given permission to provide additional information in writing. Two participants provided additional information in written form.

### Participants

Twelve parents of children diagnosed with an autism spectrum disorder, including Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), or Asperger's Syndrome, from four different geographical locations within a pre-designated state in the Midwest were ultimately selected and interviewed. The following

background information provides an overview of each participant's experience. All participant names are pseudonyms.

#### *Anne*

Anne has a kindergarten age child, Brandon, diagnosed with autism. Brandon's diagnosis changed periodically between Pervasive Developmental Disorder-Not Otherwise Specified and autism beginning at the age of two and one half years. The diagnosis he was given was dependent on the specialist conducting the assessment. Anne was forced to quit her job due to the inability to find daycare for Brandon and become a stay-home mom. Anne spent much of her time educating herself about autism spectrum disorders and has become a leader for a support group for parents.

#### *Beth*

Beth has a child, Cory, diagnosed with autism. Beth had many delays in her search for answers with regard to Cory's behavior and was told to "wait and see" and that he was fine. Beth was given very little guidance from the medical community and became a self-learner. Beth spent 10 years earning her four-year degree and then was forced to quit her job due to the lack of appropriate daycare for Cory. Beth has become a leader for a support group for parents

#### *Dave and Lisa*

Dave and Lisa are the parents of Evan, a middle school boy, who resides full-time in a residential school placement facility. Dave and Lisa searched for answers for years and finally opted to go out of state to find a doctor who could help them. Lisa, much like Beth and Anne, was forced to quit her job due to the inability to find daycare for Evan. Dave and Lisa enrolled Evan in a school specializing in full-time education for children

with special needs after many years of trying to meet his needs on their own. Dave currently holds a leadership position in a support group for parents in their community.

*Jason and Karen*

Jason and Karen have a middle school child diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified. Hunter was diagnosed at the age of three. Upon learning of the diagnosis, Jason and Karen were in the room with the doctor while Hunter screamed and screamed. The doctor put his hands in the air and said to them, "I don't know what on earth you are going to do with this kid." With the lack of guidance given to them from the medical community, Jason and Karen relied on Internet searches for information and interventions. They became part of a core group of parents who pushed for educational programming specific to children with autism in their school district.

*Cindy*

Cindy is the mother of Landon, an 8-year-old boy diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified. Cindy was employed as a nurse for many years and currently works in the field of early intervention. Cindy often referred to Landon as her "little rainman" prior to his diagnosis. Cindy was not given any direction from the medical community upon learning of the diagnosis and has taken it upon herself to bring Landon to a Defeat Autism Now (DAN) doctor out of state. DAN doctors specialize in the treatment of children with autism. Cindy has helped create a non-profit organization dedicating the funding raised to the treatment of children with autism and for financial support to parents.



### *Genna*

Genna is the mother of Jonah. Jonah is a 5-year-old boy who was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified at the age of three. Jonah has extreme meltdowns that typically last 45 minutes to an hour, making it difficult for Genna to take him on community outings. Genna currently works at Jonah's preschool and is increasing her knowledge in the area of autism by taking online courses. The computer became Genna's best friend as she searched for answers for her child. Genna has also helped to create a non-profit organization specializing in the treatment of children with autism and funding support options for families of these children.

### *Sean and Tonya*

Sean and Tonya have a middle school boy, Tommy, diagnosed with Asperger's Syndrome. Tommy was diagnosed in the 3rd grade. Sean and Tonya questioned Tommy's development at age three, as he was engaging in many repetitive actions. He was previously diagnosed with Obsessive Compulsive Disorder, Attention Deficit Disorders, and sensory integration problems. Tonya, a speech pathologist, was working with children on the autism spectrum and began to question Tommy's diagnosis. Sean and Tonya brought Tommy to see a psychologist and the diagnosis of Asperger's Syndrome was confirmed. Sean feels they have an easier situation than most parents who have a child diagnosed with an autism spectrum disorder due to Tonya's knowledge. Sean and Tonya were left to struggle through possible intervention paths on their own and feel that, without Tonya's expertise in working with children on the spectrum, they would have had a much more difficult situation on their hands.

### *Dennis and Sandy*

Dennis and Sandy are the parents of a recent high school graduate diagnosed with Asperger's Syndrome. Even though Dennis and Sandy questioned Max's development at the age of three, they did not get an accurate diagnosis for Max until he was in the 11th grade. Prior to his diagnosis of Asperger's Syndrome, Max was on an Individualized Education Plan for a learning disability in the areas of reading and math. After watching a news report on autism spectrum disorders, they asked for an evaluation. Max received the diagnosis of Asperger's Syndrome shortly thereafter. Dennis and Sandy feel lost with this new diagnosis. They realize that Max has many social disadvantages and worry about his future now that he is entering the adult world.

### *Rigor and Trustworthiness*

Throughout my work as an educator during the past 10 years, I have had the opportunity to work with numerous families and their children. In my years as a special education teacher, an autism-specific teacher, a general education teacher, and a Title reading teacher, I have worked firsthand with many families of children with special needs and learning difficulties. During this time, I found that the parents of children with an autism spectrum disorder had unique experiences and hardships that the families of the typically developing children, as well as children with other special needs, did not encounter. These unique experiences included a frustration with the medical field while searching for a diagnosis, as well as the lack of information provided to them after finally receiving a diagnosis of autism spectrum disorder for their child. These parents became self-learners via parent support groups and the Internet. Moreover, these parents were financially responsible for their child's treatments. They continually battled with their



insurance companies with regard to covering the costs of these interventions, many without success. This financial burden was heightened when one of the parents was forced to quit his or her job due to the lack of childcare available for a child with high needs. In addition, the parents continually struggled with community outings and were asking for assistance with this on a regular basis. These struggles occurred regularly and made it difficult for the parents to dedicate time to their other children, friends, and family. As a result, many of these parents relied on their local parent support groups for friendships.

Having an extensive background knowledge of autism spectrum disorders, as well as the struggles that the parents with whom I have worked with have, it was extremely important to ensure that researcher bias was addressed. The validity of research refers to the degree to which the data collected from the study are accurate (Glesne, 2006). According to Maxwell (2005), “internal generalizability refers to the generalizability of a conclusion *within* the setting or group studied, while external generalizability refers to its generalizability beyond that group or setting” (p. 115). Although it is impossible to assure that threats to validity in a phenomenological study were not present, the following steps were utilized to ensure that the results of this study are free of validity threats and increase the credibility of the conclusions:

1. “Triangulation – use of multiple data-collection methods, multiple sources, multiple investigators, and/or multiple theoretical perspectives” (Glesne, 2006, p. 37). For this study, observations, interviews, and member checking were used.



2. Member checking – “sharing interview transcripts, analytical thoughts, and/or drafts of the final report with research participants” (Glesne, 2006, p. 38) to be sure the participants’ ideas are being represented accurately.
3. Peer examination – the process of “asking colleagues to comment on the findings as they emerge” (Merriam, 1998, p. 205). This was utilized to combat researcher bias. Three experts in the field, a child psychologist specializing in autism spectrum disorders, a teacher specializing in the education of children with autism spectrum disorders, and a special education coordinator involved in the origination of an autism education program, have been consulted throughout this study. Throughout the process of conducting interviews and analyzing the data, the professionals were consulted, both through conversation and emails, with most actual conversation occurring with the school psychologist. All three professionals were sent copies of the data analysis forms, as well as the information displayed in Table 1: Data Analysis. At this time, the professionals were asked to read through the information and provide me with their opinions. All three professionals submitted their opinions to me in writing. Further clarification was gathered, when necessary, via email and personal conversation.
4. Saturation of data – Interviews were conducted until saturation of data had been reached. Saturation of data can be defined as the point at which no new information or themes are observed in the data (Glesne, 2006).
5. “Rich, thick description – writing that allows the reader to enter the research context” (Glesne, 2006, p. 38).

## Data Collection and Analysis

“The main categorizing strategy in qualitative research is coding” (Maxwell, 2005, p. 96).

In qualitative research, the goal of coding is not to count things, but to “fracture” . . . the data and rearrange them into categories that facilitate comparison between things in the same category and that aid in the development of theoretical concepts. (Maxwell, 2005, p. 96)

After the participants were interviewed, the following steps were employed to “provide an understanding of the common experiences of the participants” (Creswell, 2007, p. 61). First, the interviews were transcribed (Appendix D) and then examined for “significant statements’ [or] sentences that provide[d] an understanding of how the participants experienced the phenomenon” (p. 61). Next, clusters of meaning were developed into themes (Appendix E). These “significant statements” and themes were then used to create the formulated meaning of the participants’ experiences. Finally, the formulated meaning statements were compiled to write a composite description that captured the essence of the participants’ experience in hopes that the reader would walk away with an understanding of what it would feel like to walk in the shoes of a parent who has a child diagnosed with an autism spectrum disorder.

Reflection on these formulated meanings led to the assertion that parents who have a child diagnosed with an autism spectrum disorder are in a constant state of stress. This stress originates with the realization that their child is not developing normally and continues through the diagnostic process. This stress is chronic, occurs daily, and is the result of raising a child on the autism spectrum while continually searching for answers. The stress persists throughout periods of crisis, such as preparing for transitions, both big

and small. The codes, categories, and formulated meanings are summarized in Table 1:  
Data Analysis. Support for each of these formulated meanings is presented in Chapter  
IV.



Table 1. Data Analysis.

Codes	Categories/Themes	Formulated Meanings	Assertion
Warning sign Questioned development Early indicator Lost milestones Diagnosis	Early Signs and Diagnostic Struggles → →	Eight out of 12 parents interviewed identified specific concerns about their child's development between the ages of 12 and 18 months. Four out of 12 parents were seeing signs by the age of three years. Despite these early concerns, the diagnosis of an autism spectrum disorder was not confirmed until years and/or doctor visits later.	Parents who have a child diagnosed with an autism spectrum disorder are constantly faced with barriers and complications while raising their child. Many of these complications are chronic, in that they continue throughout numerous everyday experiences and are the direct result of raising a child on the autism spectrum while continually searching for answers. The complexity of this experience persists throughout periods of crisis.
No knowledge Self-learner Self-advocate No guidance No plan for treatment	Lack of Guidance From Medical Professionals → →	Eleven out of 12 parents interviewed felt lost after their child was given the diagnosis of having an autism spectrum disorder. They felt they were given very little guidance from the medical community, after receiving their child's diagnosis, with regard to helping their child. In addition, these parents felt they were not made aware of therapy options for their child. Therefore, these parents took the initiative to educate themselves about their child's disorder and optional therapies.	
"Lost" job Daycare issues Treatment expense	Limited Daycare Options and Financial Stressors → →	Four out of 12 parents interviewed believed they had limited options for daycare. They struggled finding and keeping childcare. They had to quit their jobs in order to care for their child with an autism spectrum disorder. All of the families interviewed were also financially responsible for many of the interventions utilized. Both of these became financial stressors for the families.	

Table 1 (cont.)

Codes	Categories/Themes	Formulated Meanings	Assertion
Family stress Lack of support	Torn Between → →	Six out of 12 parents interviewed expressed feelings of being torn between their child with the autism spectrum disorder, as well as other family members and friends.	
Anxious Worried Important to me Questioning future	Concerns for the Future → →	Ten out of 12 parents interviewed expressed feelings of concern for what the future will hold for their child. They are anxious and worried about the unknown.	
Judged by others Invisibility of autism Spectrum disorders Public struggles	Judgement of Others → →	Five out of 12 parents interviewed expressed feelings of being judged by the public due to the fact their child may look "normal" but does not behave that way. Their child may have a meltdown in a public place and the stares of strangers are difficult for these parents to bear. Their child may also engage in abnormal behaviors, which, in turn, lead to stares.	
Vaccinations Food allergies Innate sensitivities Illness – never healthy	Parent Perceptions of Vaccinations → →	Seven out of 12 parents interviewed felt that vaccinations may have played some role in causing their child's autism. They felt that this may be due to an innate sensitivity their child had, timing of the vaccinations, or multiple doses given at the same time.	

## CHAPTER IV

### PRESENTATION OF FINDINGS AND DISCUSSION OF THE FINDINGS WITH REFERENCE TO THE LITERATURE

The purpose of this chapter is to present the findings of the study and discuss these findings with reference to the literature. Specifically, the formulated meanings generated from the significant, meaningful statements of the interview participants are presented. These formulated meanings resulted in seven themes, which include early signs and diagnostic struggles, lack of guidance from medical professionals, limited daycare options and financial stressors, torn between, concerns for the future, judgment from others, and parent perceptions of vaccinations. Several interview participants' stories and statements are shared to support these formulated meanings.

#### Theme One – Early Signs and Diagnostic Struggles

Eight out of 12 parents interviewed identified specific concerns about their child's development between the ages of 12 and 18 months. Four out of 12 parents were seeing signs by the age of three years. Despite these early concerns, the diagnosis of an autism spectrum disorder was not confirmed until years and/or doctor visits later.

Six of the families or eight of the parents interviewed have children diagnosed with autism or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Of these parents, all had concerns about their child's development between the ages of 12 and 18 months. Two of the families or four of the parents interviewed have children diagnosed with Asperger's Syndrome. These parents discussed concerns with



development at the age of three. All of the parents interviewed brought their concerns to medical doctors. However, the diagnosis of an autism spectrum disorder was not confirmed for these families until years and/or doctor visits later. Anne described when she first noticed concerns with Brandon's development.

Brandon was meeting his milestones at 12 months. It was at 15 months when Right Track came in and we were seeing things that made them come back in a month or two for another evaluation and he was not passing these. We started to be concerned, because he wasn't making the evaluations.

Anne later portrayed her feelings about the diagnosis.

I think a doctor should have done it, saw the red flags. I think that when I took Brandon in to his appointments, they should have noticed it. I think that missing autism is like missing a train wreck. I think somebody should have said, "Looks like your child has autism." I would have hated them, but I think that is their job. I think they should have told me that. Absolutely.

Beth also described concerns with Cory's development, both at 12 and 18 months of age.

A little after 12 months of age Cory started having a lot of night wakings where he would get up and also didn't want to be rocked anymore, he would fight it. He started waking a lot at night and arching his back, really stiff like a back. He also had constant diarrhea. He was sick a lot, which I blame a lot of his misery on. He would imitate, crawl, he would walk, sit up. He did everything textbook fashion, but he didn't talk a lot. At about 18 months, my husband and I wondered what was wrong here. We noticed something wasn't quite right. We would pull him in the wagon in the spring and he wouldn't even look at anything, he just had this glazed over look on his face. My mother-in-law even said that he wouldn't look at her when she would say his name and we thought it was due to the ear infections, maybe a hearing loss, you know. But then, that summer we hired a high school kid to come and watch the kids so I wouldn't have to take everyone out in the morning and that was when he started banging his head, bad. He was very miserable; he did not talk or coo at all. He would bang his head on the floor and the door and then on the wall when I would leave in the morning.

When Beth brought her concerns to the doctor she had difficulties, as well.

I made an appointment with a local physician and he said he was fine. I said, "He is not playing. He's banging his head on the floor, and he won't talk." The doctor said he was fine that everyone had been talking for him. I was like, "Okay." I left saying, "That is not right." So, I went to a bigger city to find a

pediatrician who knew everything about autism, supposedly. We walked in and Cory banged his head on the floor and then went to sit in the corner. And then, the doctor said, "He is not autistic. He is fine." He said that he was banging his head because he was frustrated because he couldn't talk.

Beth continued depicting her frustration.

I think the medical community was definitely a failure. Definitely. I was disappointed with the first two pediatricians. If I would have been one of those mothers who would have been relieved at the fact that they said he was fine, I probably would not have seen another doctor until I really had to. However, I needed to keep searching for that answer.

Dave described concerns with Evan's development.

Evan developed normally throughout his first year. He crawled on time, did all the normal things that he was supposed to do. He was really a fun kid – a little clingy to mom, but a fun kid. At about a year and maybe a few months, we noticed that he wasn't talking. He wasn't saying mom or dad or any of these sorts of things and it was very hard to direct him. You couldn't tell him anything. He had his own mind on how he was going to do things. He wouldn't listen. He was very noncompliant. The speaking was the biggest thing. In terms of having an autism disorder, at about a year we noticed he was not talking. We didn't think autism at that time, but looking back that would have been one of the first signs that we saw . . . even younger than that, had we known all the signs, we would have questioned his clinginess and his clinginess to mom and his noncompliance. He also loved to swing. This would have been a sign to us now.

Lisa added to Dave's concerns.

I think it was about 18 months that I really noticed. He just didn't play like the other kids on the playground. He had this fascination with watching wheels turn on cars.

Dave and Lisa brought their concerns to their doctor many times. After seeing a news program on autism, they brought their concerns back to their doctor. The lack of direction and of a diagnosis from their own doctor led them to seek a specialist in a bigger city.

We went back to the doctor and I told the doctor that I felt bad about diagnosing my child off of the TV and I certainly didn't want to do that, but I said, "Could our child have autism?" I said that I saw this show on *20/20* and Evan acted just



like that. He took his glasses off and put them on the table and set his pen down and then he looked at us and said, "Dave, one thing we know for sure is that your son does not have autism." Then he kind of mumbled about autism being the word this week, because he already had two other parents in this week thinking their sons had autism. We felt kind of small and wished we hadn't said anything, and out the door we went. We were very, very disappointed with the local medical system here. We just struggled with it.

Dave continued explaining their experience with a specialist in a bigger city.

The doctor down there didn't state that his diagnosis was autism, but he went over the findings and how each person that reviewed Evan said the same things. Then he pulled those things off and put them into another chart/calculator, and it came up with a more than average possibility that this child has autism. Then he said, "I am not saying your child has autism, but I think it is something we should be focusing on as we move forward." In the back of my mind, I went back to this TV show that I saw and thought that I had seen some of these things and it made sense to me.

Tonya described when she first questioned Tommy's development.

I want to say it was around age three that I started noticing things. He was doing a lot of repetitive actions and wanted to do the same thing over and over. Just because I am a speech pathologist I noticed it more than my husband and was clued into it. I would mention it to my friends and they would be like, "No, Tonya, you are looking too much into this." He was finally given his actual diagnosis of Asperger's when he would have been going into 2nd grade.

Tonya explained the diagnostic process, as well.

Tommy was seeing our family physician for "attention," but I had a gut feeling he had Asperger's Syndrome. We requested some testing be done at school due to some language concerns, as well as attention concerns. He was diagnosed with ADHD (Attention Deficit Hyper-Activity Disorder), OCD (Obsessive Compulsive Disorder), sensory integration, and language delays. Still in my gut I felt it was Asperger's. Finally, when going into 2nd grade he still had those repetitive behaviors and he still did some very different things. We knew he was attention deficit, and OCD, and had some sensory integration problems. Even though he had all of these things, something just didn't seem quite right. So, then we took him to another doctor to see if it might be Asperger's. At that point I was reading a lot more and dealing with a lot of kids in the school system with Asperger's. The psychologist that we took him to confirmed the diagnosis of Asperger's.



Sandy also had concerns about her son's development around the age of three.

When he was very young, around three years old, he didn't like the feel of grass on his bare feet. He was very sensitive to touch and loud noises. He didn't like to eat anything too cold or frozen, like popsicles and ice cream. We had him in t-ball and I remember that his hands flapped when he ran. Also, when he got interested in something it was to the point of obsession.

Max did not receive the diagnosis of Asperger's Syndrome until he was a junior in high school, when his parents questioned his learning disability and OCD diagnosis and asked for further evaluations.

Three professionals in the field were asked to review the formulated meaning statements generated from the interviewee's meaningful statements. When asked to reflect upon the early signs and diagnostic struggles that these parents had encountered and described, the school psychologist stated that she partially agreed with the findings.

I agree that many parents of children with autism spectrum disorder have concerns about their child's development before the age of two or three. I disagree with the statement that diagnosis is not confirmed until years later, because this is specific to individual children and the severity of their autism spectrum disorder and is vague. Children with Asperger's Syndrome are usually not identified until well into elementary school, but many children with more severe autism are identified before kindergarten.

I feel that the school psychologist misinterpreted my findings because her statement "Children with Asperger's Syndrome are usually not identified until well into elementary school, but many children with more severe autism are identified before kindergarten" ultimately agrees with my formulated meaning. The parents in this study who have children with autism and PDD-NOS expressed concerns regarding their child's development between the ages of 12 and 18 months. Even if these children are receiving a diagnosis prior to kindergarten, it is years and doctor visits after the parents' initial concern. In addition, the parents of children with Asperger's Syndrome expressed

concern regarding their child's development around the age of three. If these children are not diagnosed until well into elementary school, again this is years and doctor visits after the parents' initial concern. Therefore, the formulated meaning is actually in agreement with the school psychologist's opinion.

Another expert in the field described her thoughts when asked to reflect upon the diagnostic process.

I would agree that there is a frustration among many parents of kids on the autism spectrum that their concerns weren't taken seriously early on when reported to the family physician. With the importance of early intervention for kids on the autism spectrum, valuable time can be lost.

In summary, the parents interviewed in this study who brought concerns to their doctors between the ages of 12 and 18 months finally received the diagnosis prior to kindergarten, but many doctor visits later and approximately three years after their initial concerns. Therefore, despite the diagnosis happening prior to kindergarten, it was a significant amount of time between concerns and diagnosis. The parents interviewed who had a child diagnosed with Asperger's Syndrome had years between their initial concerns and an actual diagnosis. Max was not officially diagnosed until he was a junior in high school and Tommy did not receive an accurate diagnosis until he was in 2nd grade. This delay in diagnosis results in lost time for appropriate interventions, resulting in parents and educational professionals playing catch-up. Early intervention is the key for later success and better prognosis for children on the autism spectrum. According to Taylor et al. (2009), children who receive interventions specific to autism spectrum disorders by the age of three show greater improvements than children who do not receive these interventions until the age of five. In addition, it has been determined that



interventions that begin at an earlier age result in a better prognosis for the child later in life.

Several researchers have argued that there are significant indicators present in children with autism spectrum disorders that present themselves prior to the age of 24 months. Baranek (1999) argued that there are slight indicators of autism present as early as 9 to 12 months in the areas of sensory processing, sensory-motor functions, and social responses. In addition to these early indicators, the lack of pointing at objects of interest and impairments in gaze monitoring and pretend play, which are all items included on the CHAT, were pinpointed as early indicators of autism spectrum disorders (California Departments of Education and Developmental Services, 1997). Moreover, Beauchesne and Kelley (2004) proposed that within the first year of development children with pervasive developmental disorders display impairments in social interaction, lack a social smile, have hypotonia, display poor attention, and have unusual visual interests. Additionally, by the second year of development, these children tend to ignore people, have a preference to be alone, display an empty gaze, and have a lack of gestures and emotional expression. Furthermore, Landa and Garrett-Mayer (2006) suggested that there are variations in typical language development, along with language delays by 24 months of age.

In addition to these studies, parent interview studies have also been conducted which support the notion that autism presents itself at an early age, leading parents to question their child's development between the ages of 12 and 24 months. Schall (2000) interviewed three middle class families raising a child diagnosed with autism. Schall reported that two of these families shared that their children were developing normally



until about 18 months of age. It was at this time that these children began to lose previously acquired skills. The other family described their son as developing normally until the age of 24 months. Goin and Myers (2004) examined home videos of 12 typically developing children and of 12 children diagnosed with infantile autism. They found that “5 out of 19 specific behaviors significantly differentiated the children with autism from the typically developing children during the first year of life” (p. 6). These included poor social interaction, the lack of a social smile, no appropriate facial expressions, hypotonia, and being easily distracted. From the ages of 12 to 24 months, they continued to find differences in development. The children with autism tended to ignore others around them, preferred to play alone, had a lack of eye contact and appropriate gestures or expressive postures, were very calm, displayed unusual postures and hypoactivity, and lacked the expression of emotions. Furthermore, Baird et al. (2003) reported that most parents express concerns when their child is about 18 months of age. In addition, when early videos of these children are examined the following characteristics are present by 12 months of age: lack of social smile and appropriate facial expression, poor attention, impaired social interaction, ignoring people, a preference for aloneness, a lack of eye contact, a lack of appropriate gestures and emotional expression, less looking at others, less pointing, and less showing of objects to others.

Despite parents expressing concern to the medical community regarding their child’s development at such early ages, several studies report that parents of children with autism spectrum disorders experienced difficulty with diagnosis. Schall (2000) shared that all the families interviewed in her study “discussed an overwhelming number of visits to doctors, psychologists, hospitals and therapists to try to understand their child’s

problems” (p. 412). In addition, the parents reported that the medical professionals disregarded their experiences and opinions regarding their child. Furthermore,

Goin-Kochel et al. (2006) reported:

[the] tendency for some physicians to minimize or dismiss parents’ concerns about their children’s development and, instead, to encourage them to wait for their children to “grow out of” their problems. . . . Although the average age at which autism is diagnosed has decreased in recent years, families have continued to describe a significant struggle during the process of obtaining an autism diagnosis. (p. 440)

Heidgerken et al. (2005) argued that despite autism spectrum disorders being diagnosed across multiple settings, the path to diagnosis and treatment of the disorders is difficult and occurs after encountering many professionals. This leads to the diagnosis being prolonged, thus resulting in lost intervention time for these children.

#### Theme Two – Lack of Guidance From Medical Professionals

Eleven out of 12 parents interviewed felt lost after their child was given the diagnosis of having an autism spectrum disorder. They felt they were given very little guidance from the medical community, after receiving their child’s diagnosis, with regard to helping their child. In addition, these parents felt they were not made aware of therapy options for their child. Therefore, these parents took the initiative to educate themselves about their child’s disorder and optional therapies.

Anne reflected on her feelings of being lost after receiving Brandon’s diagnosis.

I cannot believe that we saw so many people and nobody gave us any real direction. No real direction at all. I kept hearing about specific therapies, like floortime and ABA [applied behavior analysis] and other things. I thought it was odd that no one was really pushing any of them on us, but I was starting to hear about kids that did really well with some of these. I remember that even though the doctor agreed with the diagnosis of autism, he told us that it was a lifelong disability, that symptoms progress, this isn’t something he grows out of, he will



get worse, and speech may not happen. Practically in the same sentence that he told us this was a lifelong disability, he also didn't need to see him for another year and didn't give us any direction. These [autism spectrum disorders] are one of the most common childhood disorders right now: 1 in 150 kids, let's be generous and say 1 in 250 kids or 1 in 500 kids. I should not feel alone. I should not feel lost. I should not wonder what do we do next. I should be given more guidance.

Karen recalled her frustration with the lack of direction given to them upon receiving Hunter's diagnosis.

After the three hours of testing, Hunter had to sit in a room with a doctor and it was pretty bad. He screamed and screamed and screamed. He cried and cried and cried. At this point the doctor just put up his hands and said, "I don't know what on earth you are going to do with this kid." And that was kind of his diagnosis: He has autism and cannot imagine what we were going to do. So, that was kind of hard. Tears were rolling down my face and Hunter was screaming, and he just said that he didn't know what we were going to do. I said that he was the one that was supposed to tell me what to do and was not given one answer, not a single one. No direction whatsoever. We just left there devastated. I didn't know what we would do. Then, after that we read tons of things on the Internet about autism. We got our autism degree on the Internet.

Karen continued.

Probably the best explanation I have heard about it is that if your kid has cancer they say you need to do this, this, this, and this, and there is a set plan. There is just no one stop set plan for autism and you just don't know where to begin or what to do. I think the biggest thing that we did was to not give up and to do as much as we can.

Justin added to Karen's feelings.

It is sad that there are not enough people around that are knowledgeable about autism therapies. There are no avenues to take when trying to find where to go from here. Even if they would say that there are many different therapies and give information on them . . . that would help. You would think that the hospital or somewhere there would be information on therapies. Nobody really did.

Cindy also educated herself on autism therapies.

From the diagnosis we were not given any real direction, just told that behavior modification and therapy were what was needed, but nothing beyond that, such as what to pursue and when. They made it sound pretty hopeless. I started doing my



own research. We don't see a psychologist and psychiatrist, because we would go to the appointments and they would ask me what we were doing. I felt like they should be telling me what I should be doing, not the other way around. As it turned out I would tell them what we were doing, where we were going, and I just thought it was stupid. Therefore, the computer was my best friend after the diagnosis.

Tonya stated that it was very difficult not having any answers after the diagnosis and that she had to rely on her knowledge, as a speech language pathologist, and self-education to help Tommy. She also had to use this knowledge to educate others who worked with him.

I feel that a lot of what has happened for Tommy has been a result of the research that I have done, as a parent. The things that we have asked for, and the services put in place have been things that I have asked for. Again, the school system has been great, but there are still so many people who don't know or aren't educated about Asperger's or the autism spectrum.

When asked to reflect upon the lack of support given to these parents from the medical field, the special education coordinator stated:

I would say that the medical community, in general the family doctors, could use more training in the area of autism. I would hope that the majority of psychologists/psychiatrists would have more guidance for parents. I would say, however, that in my experience, the parents that I have worked with have had to learn much on their own.

Another expert in the field of autism described her views regarding parent support and education from the medical community.

I feel these statements vary based on different experiences of individual families and the needs of children. I feel that parents of children with autism spectrum disorders feel lost and parents may mourn after receiving the diagnosis. I agree that some parents may receive little guidance from the medical community and in some areas of the country it is difficult for parents to even get a confirmed diagnosis from medical professionals, which prevents children from getting proper treatment and special education services. I agree that parents are often not made aware of therapy options or parenting styles that would benefit their family. Some parents are able to educate themselves about this disorder and therapies but,

unfortunately, if parents are uneducated or uninformed themselves, this is not likely to happen.

To summarize this last theme, the parents interviewed in this study were given very little information after receiving the diagnosis with regard to where to go next or what interventions were research based and proven to be effective for children on the spectrum. Therefore, many parents took the initiative to educate themselves.

Unfortunately, most often they relied on the Internet. While there is a vast amount of information on the Internet regarding autism and possible interventions, it is also difficult to decipher which interventions are research based and proven and which interventions are the newest hoaxes. Therefore, having the guidance of professionals in the field is essential to ensuring that effective interventions are utilized.

McCabe (2008) conducted a survey with 78 parents who have a child diagnosed with autism. Of these 78 parents, 13 were selected for follow-up interviews. One major theme that emerged from the study was feelings of confusion and despair due to the lack of information provided after the diagnosis of the autism spectrum disorder. In the interview study conducted by Schall (2000), Sydney Boarder stated:

Once they told us it was autism, I knew what to do. I knew that I had to go to the library and read and find other people like us who had the same thing. That's right, the doctors, even Children's Hospital didn't hook us up with the Autism Society. But, that's how we did it. I tried to learn as much as I could. (p. 415)

In addition, Baird et al. (2003) discussed the importance of providing parents with information and an action plan after the diagnosis is given to educate and empower parents with appropriate resources.



### Theme Three – Limited Daycare Options and Financial Stressors

Four out of 12 parents interviewed believed they had limited options for daycare. They struggled finding and keeping childcare. They felt they had to quit their jobs in order to care for their child with an autism spectrum disorder. All of the families interviewed were also financially responsible for many of the interventions utilized. Both of these became financial stressors for the families.

Anne described her frustration with limited daycare.

I lost my job. Most people would view it as I quit my job to stay home with my kids. (Crying) I really lost my job. There was nobody to take care of him. It is easier to say that I quit my job to stay home with my kids and that I am lucky to do so, but that is not factual. That is not factual.

Beth also had to quit her job to stay home due to the lack of daycare available to her. She stated:

It took me 10 years to get my four-year degree and then I ended up quitting my job to stay home. It is very lonely, and it is something that people who have experienced it can really only talk about.

Dave and Lisa also had to make a choice regarding one parent quitting a job to stay home with Evan. In their case, it was Lisa.

It is tough because usually both parents are working and trying to find a fit for a child with special needs. It gets to be a load. We had Evan in daycare when Lisa went back to work. All of a sudden we got a call from the daycare center saying that they didn't really know if Evan was the right fit for childcare. Basically, he got kicked out of daycare and I have heard that from other parents, as well. We had no choice. One parent needed to quit working. In our case it was Lisa. I am sure in most cases it is the mom who ends up quitting work to take care of the child. I can tell you about several families where the mom has quit her career to stay home for this same reason.

The lack of one parent's income may become a financial stressor for the family.

In addition, the parents expressed that they are financially responsible for many of the



therapies they choose for their child. Beth shared her feelings of anger at the lack of financial support for her child's therapies:

I get angry because the medical field and insurance companies in our state will not help me. They will not pay for anything. I would say financially it is a huge struggle when you are trying to help your child. Nobody wants to be accountable for any of it.

Upon hearing that many of the parents interviewed felt they had limited options for daycare, that they struggled finding childcare, and some had to quit their jobs in order to care for their child with special needs, the special education coordinator stated:

This is very true and very stressful for parents.

The school psychologist agreed with this, as well.

I agree that there are little options for daycare for families of children with autism (as well as many other disabilities). I agree that some parents do quit their jobs in order to care for their child, depending on the severity of their child's needs and other family support.

In summary, finding childcare for children with autism spectrum disorders can be challenging. The parents interviewed in this study were often forced to make a decision regarding one parent quitting his or her job and staying home. Also, many of the therapy options, including applied behavior analysis, are expensive and the responsibility of the parents rather than their insurance companies. The lack of one parent's income and the added financial responsibility for therapies can become a hardship for many of these families. Additional research in this area was not found.

#### Theme Four – Torn Between

Six out of 12 parents interviewed expressed feelings of being torn between their child with the autism spectrum disorder, as well as other family members and friends.

Dave described his feelings of being torn between Evan and his other family members and their friends.

We are torn between our own lives at home, our work, and whether we should be with Evan more or with relatives. That is probably the biggest thing. Some weekends we would like to go home and visit Lisa's mom and dad or Lisa's brothers and sisters, but we feel we need to see Evan every weekend. We are torn a little bit that way or sometimes we would like to see friends. That tears us a little bit, but we are making it work.

Cindy has three other children that she has to care for in addition to Landon. She has difficulty dividing herself between them and is constantly torn between them and Landon, along with time for her husband. She expressed the stress of this and the guilt she feels.

I think I get torn between how to get Landon better and my other three kids. I have talked about this to other parents, too. I know that he needs me the most, so I justify that in my mind. I want to perfectly divide myself up between my husband and my other kids and my job and myself. However, I think that guilt component would still be there.

Beth has many feelings of guilt associated with the amount of time she spends with Cory and her other children, as well as not being able to do things as a family.

There is that guilt with the other children. My life is consumed with autism and their lives are consumed by autism. Also, the fact that mom and dad cannot go everywhere with them, that we usually have to split up is not fair to them. There are all sorts of things that we want to do as a family that we can't. It is way too hard to bring Cory. We cannot go out to eat as a family. This is hard on everyone.

Karen has a daughter who is older than their son Hunter and feels badly that so much of their time and energy is focused on Hunter's therapy.

I think about his older sister, because we are so focused on all of Hunter's therapy. We are still trying to help her, but feeling like we don't give her enough time. She tells us that we don't give her enough attention, that it is always her brother. I often feel torn between the two of them and trying to give them enough time each.



The experts were asked to reflect upon the idea that some of the parents interviewed feel torn between their child with autism and their other family members.

The school psychologist agreed with this.

They are torn between their child with autism and their other typically developing children who may not get as much attention because of the needs of the child with autism. In addition, they may feel separated from extended family members who do not want to spend time with their family, may feel uncomfortable around them, may be overly judgmental or blame the parents of the autistic child.

The special education coordinator agreed, as well.

This is also very true. The child on the autism spectrum consumes a lot of time, money, energy, effort, and emotional reserves. Many times the impact on the family unit is impacted greatly.

In summary, the parents interviewed for this study had a difficult time dividing their time between their other children, family members, and friends. When spending their time and energy on their child with autism, they had feelings of guilt regarding their other children. When focusing their time on their children without an autism spectrum disorder and other family members and friends, they experienced feelings of guilt because they were not spending this time on improving their child's disorder. These parents experienced this sense of being torn between on a constant basis and struggled with finding a balance. Rao and Beidel (2009) reported that parents who have a child with high functioning autism "may participate in fewer social and recreational activities than families with children with no disorder" (p. 449), due to the amount of commitment they have to their child with autism and the difficulties associated with community outings.



## Theme Five – Concerns for the Future

Ten out of 12 parents interviewed expressed feelings of concern for what the future will hold for their child. They are anxious and worried about the unknown.

Cindy exemplified this concern.

I worry about his future and if something would happen to me, what would happen to him. I am kind of the instigator for all of this.

Dave expressed his concern about Evan's future, as well.

Every day Lisa and I wonder about Evan's adult life – and if we think too much about it, we can make ourselves literally sick. We just have to concentrate on today. However, we never know what is going to be the future with Evan. He will teach us and we will figure it out as we go along. We are anxious and we are worried a lot, certainly there is not a day that goes by that there isn't a prayer or two said for Evan. Of course, my dad and mom have both passed away now and we certainly want for them to watch over him. We worry about his future and would like to make it as trouble free and as easy for him as possible.

Beth described her worries.

I am anxious and worried about Cory's future. I don't know what else to say there. I want him to be able to have a friend and I don't care if he knows his social studies, to be honest. More importantly, I want him to have a friend so that is what we will be working on in the next couple of years. I want him just to continue to get better.

Anne expressed her hope for Brandon to become independent enough to live on his own away from home.

It is important to me that Brandon moves away from me at some point. I really don't want him to live with me forever. That is my goal. When people ask how we do this, my answer is, "I do it because I want him to move away someday." You assume that that is going to happen with your kids. It might not happen here, but I really want it to. I mean that in the bad ways and in the good ways. I do mean that I really do want him to move away someday. I want him to go away. (Laughing) I know that doesn't sound nice, but I don't want to have to raise children until I'm 80. I would like them to live by themselves. I would really like my kids to grow up and move away at some point. That is important to me. I don't know if that will happen with Brandon.

Sandy had many questions about what the future will hold for Max.

We just want Max to have a better future or more normal future. We just don't know where to go from here. Do we enroll him in college? I don't even know. Is he going to be able to get a job? I don't know. Is he going to qualify for disability services? How do we know?

Tonya worried about Tommy's future due to the cruelty of other children.

Socially things are so scary in this world right now. He can be taken advantage of so easily because he trusts everyone. Anyone could lead him to do anything and he would do it and he wouldn't think about it, even if he might think it is wrong. That is very scary for us. Kids are very cruel. As kids get older we see it more often. We try to teach him that he cannot do things that are wrong. I tell him, "Please don't do things that are wrong." It could happen – something could ruin his life, because he is a very trustworthy person.

The special education coordinator who was asked to review the themes has many years of experience working with families who have a child diagnosed with an autism spectrum disorder. She has also accumulated many years working with families who have children diagnosed with other disabilities. She speculated about the concerns these families have for their child's future.

I think any parent with a child with a disability has a fear and worry as to whether or not their child can lead a productive and fulfilling life. This fear looms large.

Another expert in the field agreed with the special education coordinator stating that this fear could be generalized to all parents who have a child with a disability. She also felt that parents of children with Asperger's Syndrome may not have this same fear.

However, all parents who were interviewed in this particular study who have a child with Asperger's Syndrome expressed a concern for their child's future. In addition, in my experiences working with parents of children with Asperger's Syndrome, I have heard them express concerns regarding their child's future. Although their concerns may be



different from the concerns parents who have a child diagnosed with autism have, they are concerns, nonetheless.

To summarize this theme, the parents interviewed in this study were anxious and worried about the unknown or future for their child. These concerns varied from having real friendships to having the ability to live and work independently. There were also concerns about what happens to their child after they, the parents, die. A survey study conducted by Easter Seals (2009) concluded that the majority of parents of children with an autism spectrum disorder are concerned about their child's future. Eighty percent of the parents surveyed reported a concern for their child's future and described a fear of their child not having enough financial support once the parents themselves die. In addition, 75% of the parents surveyed reported a concern about their child's future employment.

#### Theme Six – Judgment of Others

Five out of 12 parents interviewed expressed the feelings of being judged by the public due to the fact their child may look “normal” but does not behave that way. Their child may have a meltdown in a public place and the stares of strangers are difficult for these parents to bear. Their child may also engage in abnormal behaviors which, in turn, lead to stares.

Genna described the uncomfortable feelings she has when she goes out in public with Jonah.

It is so hard because I think people look at me like I can't control my kid, but if they only knew. I want to tell everyone, but I would never be able to leave the store. Do I put a shirt on him every day when we go to Wal-Mart that says, “I don't misbehave. I can't help it, I am autistic.”? People look at me like I cannot



control my kid, but I don't owe them an explanation anyway. But it is hard because they look at me like that.

Tonya explained the frustration she has with the lack of knowledge the general public has regarding autism spectrum disorders.

I just think our public, in general, doesn't have the knowledge about this population. Some people are so quick to judge and don't want to look beyond what is normal in their world. Just because a child looks normal doesn't mean they are normal. Like Tommy, he looks normal, but he has these goofy behaviors, and there are many times that we have been looked at and I think, "He is our son, and we are doggone proud of him." They don't know what he is going through. He may want something or there may be a schedule change. Sometimes he can handle it and other times he may melt down. However, we may be at a store or a restaurant and he may start crying and people will stare because here is this big kid crying.

Karen and Jason described an outing that Hunter and his after-school therapist took to a local pizza restaurant. While waiting for their pizza to arrive, the therapist was conversing with Hunter and he was engaging in some abnormal behaviors, such as blowing bubbles with his spit and repeating things from favorite television shows. Another table of customers asked the therapist to leave with Hunter, because they felt that his behavior was inappropriate. Karen stated that this sort of thing is very common when they go on outings and she wishes that there were something she could do. She also stated that the stares from others are very uncomfortable.

One expert in the field had the opportunity to assist parents with community outings early in her work with the autism population. She described her thoughts regarding the judgment the parents of these children feel, along with the anxiety of taking their child with them to do simple errands.

I strongly agree with the statement that the parents of children with autism feel judged by others because their child looks "normal." In addition, I feel that sometimes the parents themselves may get angry with their own children for the

same reason and may not understand that their child does not choose to behave in an autistic way. For parents of children with autism going in public causes great anxiety, even running routine errands such as shopping or eating out.

Another expert supported this.

This is absolutely true. I have heard quite a few sad stories about times when people who didn't know the "whole story" judged these kids and their parents inappropriately and harshly.

In summary, autism has been described as an "invisible disorder" in that these children typically look "normal." Due to the "normal" look of these children, people, who do not understand autism spectrum disorders, often wrongfully judge these families and children by expecting them to act and behave as a typically developing child would behave. The judgmental stares and comments made it difficult for parents interviewed in this study to take their children out in public. Schall's (2000) interview participants shared stories of rejection by family, friends, and strangers in the community. The discrimination they reported with regard to their competence as parents varied from subtle to overt judgment by family, friends, and strangers. They felt there was an assumption that there must be something wrong with them, as parents, to have such out-of-control children. In addition, the parents felt that the strangers were judging them as they stared, because their children looked normal, but behaved in an atypical manner.

#### Theme Seven – Parent Perceptions of Vaccinations

Seven out of 12 parents interviewed felt that vaccinations may have played some role in causing their child's autism. They felt that this might be due to an innate sensitivity their child had, timing of the vaccinations, or multiple doses given at the same time.



After looking at the interview affect cards and picking up the “strong conviction or belief” card, Anne discussed her views about vaccinations.

I strongly believe that immunizations are a problem. It took me a long time to say that out loud. I had to be very sure of that. I know that most people think that is just insane to think that vaccines that save lives can harm our kids. I don't think we should not vaccinate our kids, but I do think there is a smarter way instead of treating all kids the same, as if they all weigh the same, as though nothing could ever go wrong. I believe that vaccines are about pharmaceuticals making money. I blame food allergies and vaccinations for Brandon's autism – those two things combined. I don't know what came first, the chicken or the egg, but he just was not able to tolerate his immunizations like most kids can, probably due to the make-up of his body previous to the vaccinations.

Beth also discussed a similar conviction.

I would say a strong conviction or belief is that vaccines have something to do with autism – Cory's autism. In fact, there wasn't really a period when he was really healthy. Even if he was healthy for a week, he probably shouldn't have been given five vaccines at a time if he was still struggling. If I were to go back now, I surely would have done it differently. I would have vaccinated later and split them up instead of doing combination vaccines or any of that. It seems like once he got five in one day it just tipped him over the edge. There is a lot of controversy out there. You just don't know if your child might have that immune disorder that might tip them over the edge. Cory did get a flu vaccine, which nobody else in my house has ever gotten. He got it at 12 months along with three other shots at that time. After that he got really sick, really, really, really sick – asthma, bronchitis, always on medicine. He didn't sleep ever. He wasn't that get up in the middle of the night and giggle or talk to himself kind of kid autistic child, he was up crying a lot and did not feel good and couldn't breathe.

Justin described his feelings about vaccinations, as well.

I don't think autism is probably caused by vaccinations but, I do think it is the overall cause of that coming into their system, a person who cannot handle it, probably accelerates that a little bit. I am not so sure that he would be any different any other way. It is just that, it seems like a lot of things became more pronounced at that time or if it was just his age or his vaccine.

Karen added to Justin's thoughts.

I think that vaccines should not be a one size fits all sort of thing, especially for kids who are sick or behind, maybe they should spread them out so they don't get such a big jolt of them all at once. We never did give Hunter his third MMR shot;



I don't know, it was just at that time he was doing so much better that we just wanted to revert back to what he had been. Who knows if that is the right call or not, we will never know, but, I don't know. I think it is genetic, but I also think that there is something environmental that is making it happen, too. I don't know. That is the time that all these kids seem to change, so it really makes you wonder if there isn't some sort of connection, but I think it is inborn, too.

Cindy also discussed her belief about the role vaccinations play in causing autism disorders.

I always ask myself about what if I wouldn't have given Landon the flu shot when he was sick or given him vaccines when he was ill or if I should have spread them out. I think that for some kids vaccinations can definitely cause their autism. I believe that it was the vaccines that spiral them down into this world. I think that for some kids it can be part of it. I think there is definitely a genetic component, too. I think that we need to do our homework a little bit better before loading these kids up with vaccines. I think that we can spread vaccines out; that they don't need to be given nine at once. I do believe that they can wait until the age of two to vaccinate and that some kids probably shouldn't be vaccinated at all. However, I don't think it should be up to the parents to decide. I think that mainstream medicine needs to get in touch with that. I don't know when that is going to happen. I think it deserves to be researched, but it hasn't so far. I don't think that full load of vaccines caused Landon's autism. I think the vaccines that he got when he was so sick maybe pushed him over, but I think he was already somewhat there. He just wasn't as deep. That is how I feel. I am not anti-vaccine, but I am anti-crap in our vaccines. I think that we really need to look at the specific contents. It is not just the thimerisol, it is also the aluminum and lead that don't need to be there.

Dave described his view of vaccinations.

The "experts" are telling us there is not a link between autism and vaccinations. If someone finds a link, certainly I would be one of the first to have Evan tested to see if there is a causal relationship. Certainly there was no indication of Evan having any disability until around 12-18 months, so to say I believe there is no link wouldn't be exactly correct either, but we can't change what has happened.

When asked to reflect upon the idea that vaccinations may play a role in the cause of autism spectrum disorders, all experts asked did not feel comfortable drawing conclusions on this topic and did not feel they had spoken about this topic to many of the parents to give adequate thoughts. One expert stated:

I agree with this statement in that some individuals and families do believe that vaccinations may have played a role in causing autism, but there are also many families who do not believe this to be true. It is my understanding that the preservative used in some vaccinations is in question in addition to the innate sensitivity, timing, and dosage. I personally do not believe that the research is conclusive enough one way or the other to take a stance on this issue.

To summarize this theme, several parents interviewed felt that vaccinations may have played some role in causing their child's autism. They felt that this might have been due to an innate sensitivity their child had, the timing of the vaccinations, or multiple doses given at the same time. Baird et al. (2003) reported that the public anxiety regarding autism spectrum disorders has been raised due to the reports linking vaccinations and inflammatory bowel disorder to autism spectrum disorders. This has resulted in a fall in immunization rates, despite their being a lack of evidence that immunizations are responsible for autism spectrum disorders. Furthermore, the parents of children with autism spectrum disorders feel that the medical community does not take their concerns regarding the possible causes of autism spectrum disorders seriously.

#### Final Assertion

Parents who have a child diagnosed with an autism spectrum disorder are constantly faced with barriers and complications while raising their child. One of the first barriers originates with the realization that their child is not developing normally and continues throughout the diagnostic process, which often spans a long period of time and/or numerous doctor visits. This continues as parents are given very little guidance about how to proceed with therapy options, resulting in the parents becoming self-educated. The complications continue as parents become overwhelmed by the amount of information they encounter in their search for answers and are faced with



making decisions for how to proceed with helping their child. The parents feel constantly scrutinized by outsiders, making it difficult for them to engage in many community activities as a family. Many of these complications are chronic, in that they continue throughout numerous everyday experiences and are the direct result of raising a child on the autism spectrum while continually searching for answers. The complexity of decisions persists throughout periods of crisis, such as preparing for transitions, both big and small.

### Summary

Throughout this chapter, support was given for the formulated meanings that emerged from the data analysis and participants' meaningful statements. The meaningful statements resulted in seven formulated meanings and/or themes. The themes included (a) early signs and diagnostic struggles, (b) lack of guidance from medical professionals, (c) limited daycare options and financial stressors, (d) torn between, (e) concerns for the future, (f) judgment of others, and (g) parent perceptions of vaccinations.



## CHAPTER V

### SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

#### Summary

The purpose of this qualitative study was to understand the experiences and perceptions parents of a child with an autism spectrum disorder have had that may provide parents of a child newly diagnosed with an autism spectrum disorder a better experience. Utilizing the framework for a phenomenological study as outlined by Creswell (2007), the study addressed the following research question: What were the parents' experiences and perspectives with regard to their child's diagnosis and treatment options? Rolland's (1994) theory of chronic illness and Kubler-Ross's (1969) theory related to death have guided the development of interview questions for parents of children with autism spectrum disorder (Appendix B). An overview of the study and of autism spectrum disorders was provided in Chapter I. Chapter II included a review of the literature. The methodology was described in Chapter III.

In Chapter IV, the seven themes and formulated meaning statements that emerged from the data analysis were presented with meaningful statements from the participant interviews. In this chapter, a summative discussion of the study is presented. This is followed by conclusions and recommendations.

## Overview of the Methodology

For this interview study, 12 parents of children diagnosed with an autism spectrum disorder, including Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), or Asperger's Syndrome, from four different towns within a pre-designated state in the Midwest were ultimately selected and interviewed. The audio recorded interviews were transcribed and then examined for "significant statement" sentences that "provide[d] an understanding of how the participants experienced the phenomenon" (Creswell, 2007, p. 61). Next, clusters of meaning were developed into themes. These "significant statements" and themes were then used to create the formulated meanings of the participants' experiences. These formulated meanings were shared with three experts in the field of autism spectrum disorders (a child psychologist specializing in autism spectrum disorders, a teacher specializing in the education of children with autism spectrum disorders, and a special education coordinator involved in the origination of an autism education program in the field) to combat researcher bias. Finally, the formulated meaning statements were compiled to write a composite description that captured the essence of the participants' experience.

### Theme One – Early Signs and Diagnostic Struggles

Eight out of 12 parents interviewed identified specific concerns about their child's development between the ages of 12 and 18 months. Four out of 12 parents were seeing signs by the age of three years. Despite these early concerns, the diagnosis of an autism spectrum disorder was not confirmed until years and/or doctor visits later.

Eight of the parents interviewed have children diagnosed with autism or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Of these parents, all of

them had concerns about their child's development between the ages of 12 and 18 months. Four of the parents interviewed have children diagnosed with Asperger's Syndrome. These parents discussed concerns with development at the age of three. All of the parents interviewed brought their concerns to medical doctors. The parents interviewed in this study who brought concerns to their doctors between the ages of 12 and 18 months finally received the diagnosis prior to kindergarten, but many doctor visits later and approximately three years after their initial concerns. Therefore, despite the diagnosis happening prior to kindergarten, there was a significant amount of time between concerns and diagnosis. The parents interviewed who had a child diagnosed with Asperger's Syndrome had years between their initial concerns and an actual diagnosis. This delay in diagnosis resulted in lost time for appropriate interventions, resulting in parents and educational professionals playing catch-up.

Several studies in the literature support this theme (Baird et al., 2003; Baranek, 1999; Beauchesne & Kelley, 2004; California Departments of Education and Developmental Services, 1997; Goin & Myers, 2004; Goin-Kochel et al., 2006; Heidgerken et al., 2005; Landa & Garrett-Mayer, 2006; Renty & Roeyers, 2005; Schall, 2000). Signs of autism spectrum disorders are presenting themselves as early as 12 months of age. However, the diagnosis is being prolonged, thus resulting in lost intervention time for these children.

#### Theme Two – Lack of Guidance From Medical Professionals

Eleven out of 12 parents interviewed felt lost after their child was given the diagnosis of having an autism spectrum disorder. They felt they were given very little



guidance from the medical community, after receiving their child's diagnosis, with regard to helping their child. In addition, these parents were not made aware of therapy options for their child. Therefore, these parents took the initiative to educate themselves about their child's disorder and optional therapies.

They were given very little information after receiving the diagnosis with regard to where to go next or what interventions were research based and proven to be effective for children on the spectrum. Unfortunately, most often they relied on the Internet. While there is a vast amount of information on the Internet regarding autism and possible interventions, it is also difficult to decipher which interventions are research based and proven and which interventions are hoaxes. Having the guidance of professionals in the field is essential to ensuring that effective interventions are utilized. As previously stated, the parents in this study felt they did not receive guidance from the professionals that was necessary to begin treatment for their child. This may be a direct result of the rural nature of the state the parents reside in and the lack of resources available in such a state.

Similar findings regarding this theme can be found in the literature (Baird et al., 2003; McCabe, 2008; Nesbitt, 2000; Schall, 2000; Whitaker, 2002). One dominant theme that emerged from these studies was feelings of confusion and despair due to the lack of information provided after the diagnosis of the autism spectrum disorders.

#### Theme Three – Limited Daycare Options and Financial Stressors

Four out of 12 parents interviewed believed they had limited options for daycare. They struggled finding and keeping childcare. They felt they had to quit their jobs in

order to care for their child with an autism spectrum disorder. All of the families interviewed were also financially responsible for many of the interventions utilized. Both of these became financial stressors for the families.

Many of the therapy options utilized, including applied behavior analysis, are expensive and the sole responsibility of the parents rather than their insurance companies. The lack of one parent's income for some, along with the added financial responsibility for therapies for all, can become a hardship for many of these families. Research to support or disconfirm this theme was not found.

#### Theme Four – Torn Between

Six out of 12 parents interviewed expressed feelings of being torn between their child with the autism spectrum disorder, as well as other family members and friends.

These parents had a difficult time dividing their time between their other children, family members, and friends. When spending their time and energy on their child with autism, they had feelings of guilt regarding their other children. When focusing their time on their children without an autism spectrum disorder and other family members and friends, they experienced feelings of guilt because they were not spending this time on improving their child's disorder. These parents experienced this sense of being torn between the two situations on a constant basis and struggled with finding a balance. Although specific literature supporting this theme was not found, Rao and Beidel (2009) reported that parents who have a child with high functioning autism have a limited social life.

### Theme Five – Concerns for the Future

Ten out of 12 parents interviewed expressed feelings of concern for what the future will hold for their child. They are anxious and worried about the unknown.

These concerns varied from having real friendships to having the ability to live and work independently. There were also concerns about what would happen to their child after they, the parents, are no longer a part of this world. These findings are similar to the Easter Seals' (2009) findings regarding the parents' concerns for their child's future, including, but not limited to, their future financial situation and employment opportunities.

### Theme Six – Judgment of Others

Five out of 12 parents interviewed expressed feelings of being judged by the public due to the fact their child may look "normal" but does not behave that way. Their child may have had a meltdown in a public place and the stares of strangers are difficult for these parents to bear. Their child may also engage in abnormal behaviors, which, in turn, lead to stares.

Autism has been described as an "invisible disorder" in that these children typically look "normal." Due to the "normal" look of these children, people, who do not understand autism spectrum disorders, often wrongfully judge these families and children, expecting them to act and behave as a typically developing child would behave. The judgmental stares and comments made it difficult for parents interviewed in this study to take their children out in public.

These findings are similar to Schall's (2000) findings. Participants in Schall's study shared stories of rejection by family, friends, and strangers in the community.



## Theme Seven – Parent Perceptions of Vaccinations

Seven out of 12 parents interviewed felt that vaccinations may have played some role in causing their child's autism. They felt that this may be due to an innate sensitivity their child had, timing of the vaccinations, or multiple doses given at the same time.

Although literature reviewed regarding vaccinations as a contributing factor for autism spectrum disorders did not show a correlation (Baird et al., 2008; Makela et al., 2002; Schechter & Grether, 2008; Smeeth et al., 2004; Stehr-Green et al., 2003; Taylor et al., 2009), Baird et al. (2003) reported that the public anxiety regarding autism spectrum disorders has been raised due to the reports linking vaccinations and inflammatory bowel disorder to autism spectrum disorders. This anxiety has resulted in a fall in immunization rates, despite there being a lack of evidence that immunizations are responsible for autism spectrum disorders. Furthermore, the parents of children with autism spectrum disorders feel that the medical community does not take their concerns regarding the possible causes of autism spectrum disorders seriously.

### Limitations

The purpose of this study was to understand the experiences and perceptions parents of a child with an autism spectrum disorder have had that may provide parents of a child newly diagnosed with an autism spectrum disorder a better experience. Participants in the study were parents of male children diagnosed with an autism spectrum disorder, including Autism, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), or Asperger's Syndrome, who were selected for interviews from four different geographical locations within a pre-designated state in the Midwest. The majority of these parents attended regularly scheduled support group meetings in their

communities, which may have led to the possibility of groupthink. Groupthink refers to the idea that the members of the support group have cohesive ideas rather than independent thoughts. The geographic location, lack of parent participants of female children, and the possibility of groupthink, result in parents' experiences not being representative to all parents with children diagnosed on the autism spectrum.

### Conclusions

Parents interviewed in this study feel constantly faced with barriers and complications while raising their child. One of the first barriers originated with the realization that their child was not developing normally and continued throughout the diagnostic process, which often spanned a long period of time and/or numerous doctor visits. This continued as parents were given very little guidance from the medical community about how to proceed with therapy options, resulting in the parents becoming self-educated. The complications continued as parents became overwhelmed by the amount of information they encountered in their search for answers and were faced with making decisions for how to proceed with helping their child.

The parents feel constantly scrutinized by outsiders, making it difficult for them to engage in many community activities as a family. Many of these complications were chronic, in that they continued throughout numerous everyday experiences and were the direct result of raising a child on the autism spectrum while continually searching for answers. The complexity of decisions persisted throughout periods of crisis, such as preparing for transitions, both big and small.



## Recommendations

### *Recommendations for Medical Professionals*

Parents of children with an autism spectrum disorder are often left with many questions and few answers upon learning of their child's disability. Participants in this study felt lost and were given very little guidance from the medical professionals regarding what steps to take or interventions to pursue to improve their child's level of functioning. Therefore, these parents became self-educated on the topic of autism spectrum disorders primarily through information provided to them via the Internet. Once an autism spectrum disorder diagnosis is confirmed, I believe it is the responsibility of the medical community to provide parents with information regarding research based interventions and therapies for children with autism spectrum disorders. This practice would give parents a starting point for helping their child. Furthermore, medical professionals should provide the parents with information regarding where to go for additional help, guidance, and services that would assist them in getting interventions in place for their child as soon as possible after receiving the diagnosis.

### *Recommendations for Parents of Children Newly Diagnosed With an Autism Spectrum Disorder*

Having good support systems in place is an essential piece of stress management for parents of children with autism spectrum disorders. Many studies have been conducted regarding the amount and types of support provided to parents of children with disabilities and how these may impact stress levels. Having support within the nuclear family, specifically spousal support, for both the mothers and the fathers of children with disabilities, is critical for adaptation and acceptance of the child's disability (Renty &



Roeyers, 2005). Extended family and informal support from friends and neighbors are also associated with lower stress levels and helpful in assisting parents with coping with the demands of raising a child with special needs (Hastings et al., 2002; Trivette & Dunst, 1992; Trute, 2003).

Once again, at the time of the initial autism spectrum disorder diagnosis, I believe it is the responsibility of the medical community to provide parents with information about local support groups available to them. The medical professionals are responsible for diagnosing autism spectrum disorders. Therefore, it is their responsibility to provide parents with the necessary information for where they should go next.

#### *Recommendations for Research*

Continued research is needed regarding the experiences and perspectives of parents who have children with autism spectrum disorders. As stated in the limitations, the geographic location, lack of parent participants of female children, and the possibility of groupthink, result in parents' experiences not being representatives of all parents with a child diagnosed on the autism spectrum. Conducting research studies involving parents of children with a single, specific autism spectrum disorder, children of similar age groups, and parents of female children would result in richer, more vivid experiences that may be generalized across a multitude of situations.

#### *Closing Statement*

Raising a child with an autism spectrum disorder, as well as any disability, is challenging. The provision of support, guidance, and information to the parents of these children is not only essential to ensure that these children receive proven interventions in

their programming, but it also empowers the parents with knowledge at the beginning of their journey.

## APPENDICES



Appendix A  
Research Consent Form: Subject Participation

Dear \_\_\_\_\_,

You are invited to participate in a research project. The information collected will be used to examine parental experiences and perspectives with having a child who is diagnosed with an autism spectrum disorder.

By participating in this research project, you will be interviewed at your convenience about your child's diagnostic process, healthcare experiences, and education. This will take approximately 90 minutes of your time. Additional follow-up interviews may be needed for further clarification. The interview will be audio recorded for transcription and further analysis. After completion of the study, the recordings will be stored for three years and then destroyed.

Participation in this study is voluntary and you may withdraw at any time. Confidentiality is assured, as well as anonymity. Neither your name nor your child's name will appear in connection to the information or be associated with the results of the study. Also, all consent forms will be kept separately from the research data.

If you have questions about the study or results, please feel free to call Lori Kalash at 701-230-2642 or Dr. Myrna Olson at 701-777-3188.

If you have questions regarding your rights as a research subject, or if you have any concerns or complaints about the research, you may contact the University of North Dakota Institutional Review Board at (701) 777-4279. Please call this number if you cannot reach research staff, or you wish to talk with someone else.

By signing below, you indicate that you have read and understood each of the previous paragraphs. You freely and willingly give consent to participate in this study. Your signature also indicates that this research study has been explained to you and that your questions have been answered. You understand that you may refuse to participate now, or may withdraw at any time in the future without penalty.

You will receive a copy of this form.

I give my permission to participate in the study described above.

Signature \_\_\_\_\_

Date \_\_\_\_\_

Thank you for participating in this study.

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Appendix B  
Parent Interview Questions

*My interview will include, but not be limited to, the following questions.*

1. Tell me about your child starting with the beginning.
2. Looking back, please reflect on when your child first displayed signs of having an autism spectrum disorder.
3. Describe the process of how your child became diagnosed with an autism spectrum disorder.
4. With regard to healthcare services (doctoring, dentist, optometrist, etc.), what have your experiences entailed?
5. Reflect on the effective and ineffective interventions that have been utilized with your child. (Possible follow-up: Describe what you feel the ideal educational programming for your child would include.)
6. The interviewee will be asked to read the following word cards and choose some to reflect on. The interviewee will be asked to reflect on what comes to mind with regard to their child with autism spectrum disorder and any experiences they have had:

• Success	• Important to Me	• Happy
• Anxious/Worried	• Torn Between	• Lost
• Touched/Moved	• Sad	• Frustrated
• Angry	• Trust/Rapport	• Surprised
• Guilt	• Strong Conviction or Belief	
7. Describe the types of support systems that are in place for you.
8. What advice would you give to a parent who has a child recently diagnosed with an autism spectrum disorder?
9. Please take some time to tell me anything else you would like to share with me that you have not had the chance to do so already.

\*More clarifying interview question will emerge once I begin conducting observations and interviews.



Appendix C  
Site Observation Form

Observation #:

Date of Observation:

Length and Time of Observation:

Observation Type:

Location:

Observer:

Codes	Observation Notes	Reflection/Notes

Appendix D  
Interview Transcription Form

Interview #:

Date of Interview:

Length and Time of Interview:

Interviewee Information:

Child's Diagnosis:

Interviewer:

Codes	Interview Transcription	Reflection/Notes

Appendix E  
Formulated Meaning Form

Significant Statements	Formulated Meaning	Theme Clusters



## Appendix F Debriefing

Thank you for volunteering to participate in this study. Your time and insights are truly valued. The purpose of this study was to gain insight into the perspectives of parents who have children diagnosed with autism spectrum disorders. It is believed that through your participation we may now have a better understanding of how we can positively affect the experiences of parents who have future children with autism spectrum disorders.

If you have questions about the study or results, please feel free to call Lori Kalash at 701-230-2642 or Dr. Myrna Olson at 701-777-3188.

If you have questions regarding your rights as a research subject, or if you have any concerns or complaints about the research, you may contact the University of North Dakota Institutional Review Board at (701) 777-4279. Please call this number if you cannot reach research staff, or you wish to talk with someone else.

Thank you for participating in this study.

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